DLN: 93493100003160 OMB No 1545-0047 Return of Organization Exempt From Income Tax 2018 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 Department of the ▶ Go to <u>www.irs.gov/Form990</u> for instructions and the latest information. Treasury Internal Revenue Service For the 2019 calendar year, or tax year beginning 07-01-2018 , and ending 06-30-2019 C Name of organization OSTEOGENESIS IMPERFECTA FOUNDATION INC D Employer identification number B Check if applicable ☐ Address change 23-7076021 ☐ Name change Doing business as ☐ Initial return ☐ Final return/terminated E Telephone number Number and street (or P O box if mail is not delivered to street address) Room/suite ☐ Amended return 804 W DIAMOND AVENUE NO 210 ☐ Application pending (301) 947-0083 City or town, state or province, country, and ZIP or foreign postal code GAITHERSBURG, MD 20878 G Gross receipts \$ 2,266,569 Name and address of principal officer H(a) Is this a group return for ☐Yes **☑**No subordinates? 804 W DIAMOND AVENUE NO 210 H(b) Are all subordinates GAITHERSBURG, MD 20878 ☐ Yes ☐No included? Tax-exempt status 4947(a)(1) or If "No," attach a list (see instructions) **H(c)** Group exemption number ▶ Website: ► WWW OIF ORG L Year of formation 1970 M State of legal domicile GA K Form of organization ☑ Corporation ☐ Trust ☐ Association ☐ Other ▶ Summary 1 Briefly describe the organization's mission or most significant activities OUR MISSION IS TO IMPROVE THE QUALITY OF LIFE FOR PEOPLE WITH OSTEOGENESIS IMPERFECTA THROUGH RESEARCH TO FIND TREATMENTS AND A CURE, EDUCATION, AWARENESS AND MUTUAL SUPPORT THERE ARE AT LEAST FOUR DISTINCT FORMS OF OSTEOGENESIS IMPERFECTA REPRESENTING EXTREME VARIATIONS IN SEVERITY AND AFFECTING 20,000 TO 40,000 PEOPLE IN THE UNITED STATES OI REGIONAL METTINGS IN CHICAGO AND LOS ANGELES, OI SCIENTIFIC MEETINGI IN CHICAGO, AND RARE BONE Activities & Governance DISEASE PATIENT NETWORK MEETING WERE AMONG THE SIGNIFICANT 2019 FISCAL YEAR HIGHLIGHTS Check this box ▶ 🔲 if the organization discontinued its operations or disposed of more than 25% of its net assets Number of voting members of the governing body (Part VI, line 1a) . . . 3 13 Number of independent voting members of the governing body (Part VI, line 1b) 4 12 Total number of individuals employed in calendar year 2018 (Part V, line 2a) 5 6 300 Total number of volunteers (estimate if necessary) . . Total unrelated business revenue from Part VIII, column (C), line 12 7a 0 Net unrelated business taxable income from Form 990-T, line 34 7b 0 **Prior Year Current Year** 1,485,493 1,659,231 8 Contributions and grants (Part VIII, line 1h) . Program service revenue (Part VIII, line 2g) . 0 0 10 Investment income (Part VIII, column (A), lines 3, 4, and 7d) . 204,777 177,183 11 Other revenue (Part VIII, column (A), lines 5, 6d, 8c, 9c, 10c, and 11e) 1,710 -1.073 1,691,980 1,835,341 12 Total revenue—add lines 8 through 11 (must equal Part VIII, column (A), line 12) 13 Grants and similar amounts paid (Part IX, column (A), lines 1–3) . . . 288,420 364,832 **14** Benefits paid to or for members (Part IX, column (A), line 4) . . 0 861,879 964,609 Salaries, other compensation, employee benefits (Part IX, column (A), lines 5-10) Expenses **16a** Professional fundraising fees (Part IX, column (A), line 11e) . **b** Total fundraising expenses (Part IX, column (D), line 25) ▶219,207 17 Other expenses (Part IX, column (A), lines 11a-11d, 11f-24e) . 516,842 780,309 18 Total expenses Add lines 13–17 (must equal Part IX, column (A), line 25) 1,667,141 2,109,750 Revenue less expenses Subtract line 18 from line 12 24.839 -274.409 d Balances Beginning of Current Year End of Year 2,287,475 1,768,258 20 Total assets (Part X, line 16) . 21 Total liabilities (Part X, line 26) . 447,996 271,555 22 Net assets or fund balances Subtract line 21 from line 20 1,839,479 1,496,703 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 2020-03-25 Date Signature of officer Sign Here TRACY HART CEO Type or print name and title Print/Type preparer's name Date Preparer's signature PTIN Check \square if P00118452 Paid self-employed ► THOMPSON GREENSPON Firm's EIN > 54-1029635 Preparer **Use Only** Firm's address ▶ 4035 RIDGE TOP RD SUITE 700 Phone no (703) 385-8888 FAIRFAX, VA 22030 May the IRS discuss this return with the preparer shown above? (see instructions) ✓ Yes □ No For Paperwork Reduction Act Notice, see the separate instructions. Form **990** (2018) Cat No 11282Y

Form	990 (2018)					Page 2
Pa	till Statement	of Program Servi	ce Accomplis	hments		
	Check If Sch	edule O contains a resp	onse or note to	any line in this Part III .		🗹
1	Briefly describe the	organization's mission				
		OF LIFE FOR PEOPLE SS, AND (D) MUTUAL:		NESIS IMPERFECTA (OI),	THROUGH (A) RESEARCH TO FI	ND A CURE, (B)
2	Did the organization	undertake any signific	ant program ser	vices during the year whi	ch were not listed on	
	the prior Form 990 d	or 990-EZ?				🗌 Yes 🗹 No
	If "Yes," describe the	ese new services on Sc	hedule O			
3	Did the organization	cease conducting, or r	nake significant	changes in how it conduc	ts, any program	
	services?	ese changes on Schedu				☐ Yes 🗹 No
4	Describe the organiz Section 501(c)(3) ar	ation's program servic	e accomplishmei ons are required	to report the amount of	argest program services, as mea: grants and allocations to others,	
4a	(Code) (Expenses \$	551,148	including grants of \$	228,792) (Revenue \$)
	See Additional Data		· 			
4b	(Code) (Expenses \$	455,477	including grants of \$	136,040) (Revenue \$)
	See Additional Data					
4c	(Code) (Expenses \$	70,896	ıncludıng grants of \$) (Revenue \$)
	See Additional Data					
	(Code) (Expenses \$	394,417	ıncludıng grants of \$) (Revenue \$)
	OI, PARENTS, OTHER F FACE MEETINGS WITH 2018, THE FOUNDATIO AND MORE THAN 600 I THIRD ANNUAL NATION BALTIMORE NATIONAL KENTUCKY HEALTHCAR NEBRASKA SINCE ITS I WHOM HAD NEVER ATI MEDICAL ADVISORY CO	AMILY MEMBERS AND LEA EXPERIENCED PHYSICIAN IN HELD ITS 21ST BIENNIA NDIVIDUALS LIVING WITHAL WALK-N-WHEEL FOR CAQUARIUM LOCAL VOLUN E, AND MEREO BIOPHARM LAUNCH IN 2015, OIF'S RE TENDED AN OI EVENT BEFOUNCIL MEMBERS IN FISC	DING MEDICAL EXF S, LEARN ABOUT TI, L NATIONAL CONFI I OI FOR THREE DA DI EVENT THAT DRE ITEERS AND PARTN A HELPED MAKE TI GIONAL CONFEREN DRE THESE ONE-D IAL YEAR 2019, THI	PERTS THIS CONFERENCE PF HE LATEST RESEARCH, AND I ERENCE IN BALTIMORE, MAR YS OF INFORMATION, MUTU/ EW MORE THAN 200 WALKER IER ORGANIZATIONS, LIKE T HE EVENT A TRUE SUCCESS ICE PROGRAM HAS REACHED AY CONFERENCES FEATURE I E FOUNDATION HELD TWO R I	ON OI THE CONFERENCE BRINGS TO COVIDES THE OPPORTUNITY FOR ATTI INTERACT WITH OTHER PEOPLE WHO YLAND, BRINGING TOGETHER 25 WO AL SUPPORT AND FUN THE CONFEREIS AND WHEELERS SHOWING THEIR USE DEGNA SPOLDI FAMILY FOUNDATI THE NEXT CONFERENCE WILL BE HELE MORE THAN 1,200 MEMBERS OF THE EDUCATIONAL SESSIONS LED BY OIL SEGIONAL CONFERENCES - ONE IN LOST TRACTED MORE THAN 100 PEOPLE	ENDEES TO HAVE FACE-TO- ARE AFFECTED BY OI IN JULY RLD-CLASS EXPERTS ON OI NCE BEGAN WITH OIF'S INBREAKABLE SPIRIT TO THE ION, UNIVERSITY OF D IN JULY 2020 IN OMAHA, E OI COMMUNITY, HALF OF EXPERTS INCLUDING OIF
4d	Other program serv	ices (Describe in Sched	lule O)			
	(Expenses \$	394,417 ind	luding grants of	\$) (Revenue \$)
4e	Total program ser	vice expenses ▶	1,471,9	38		

Form	990 (2018)			Page 3
Par	Checklist of Required Schedules			
_	7 11 1 1 1 1 1 1 7 7 7 7 7 7 7 7 7 7 7		Yes	No
	Is the organization described in section 501(c)(3) or 4947(a)(1) (other than a private foundation)? If "Yes," complete Schedule A	1	Yes	
_	Is the organization required to complete Schedule B, Schedule of Contributors (see instructions)? 🕏	2	Yes	
3	Did the organization engage in direct or indirect political campaign activities on behalf of or in opposition to candidates for public office? If "Yes," complete Schedule C, Part I	3		No
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? If "Yes," complete Schedule C, Part II	4		No
5	Is the organization a section $501(c)(4)$, $501(c)(5)$, or $501(c)(6)$ organization that receives membership dues, assessments, or similar amounts as defined in Revenue Procedure 98-19? If "Yes," complete Schedule C, Part III	5		No
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? If "Yes," complete Schedule D, Part !	6		No
7	Did the organization receive or hold a conservation easement, including easements to preserve open space, the environment, historic land areas, or historic structures? If "Yes," complete Schedule D, Part II	7		No
8	Did the organization maintain collections of works of art, historical treasures, or other similar assets? If "Yes," complete Schedule D, Part III	8		No
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? If "Yes," complete Schedule D, Part IV	9		No
10	Did the organization, directly or through a related organization, hold assets in temporarily restricted endowments, permanent endowments, or quasi-endowments? If "Yes," complete Schedule D, Part V	10		No
	If the organization's answer to any of the following questions is "Yes," then complete Schedule D, Parts VI, VIII, VIII, IX, or X as applicable			
а	Did the organization report an amount for land, buildings, and equipment in Part X, line 10? If "Yes," complete Schedule D, Part VI	11a	Yes	
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? If "Yes," complete Schedule D, Part VII 🕏	11b		No
	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? If "Yes," complete Schedule D, Part VIII 🕏	11c		No
	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? If "Yes," complete Schedule D, Part IX "	11d		No
е	Did the organization report an amount for other liabilities in Part X, line 25? If "Yes," complete Schedule D, Part X 🕏	11e	Yes	
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)? If "Yes," complete Schedule D, Part X	11f	Yes	
12a	Did the organization obtain separate, independent audited financial statements for the tax year? If "Yes," complete Schedule D, Parts XI and XII	12a	Yes	
	Was the organization included in consolidated, independent audited financial statements for the tax year? If "Yes," and if the organization answered "No" to line 12a, then completing Schedule D, Parts XI and XII is optional	12b		No
13	Is the organization a school described in section 170(b)(1)(A)(II)? If "Yes," complete Schedule E	13		No
14a	Did the organization maintain an office, employees, or agents outside of the United States?	14a		No
Ь	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? If "Yes," complete Schedule F, Parts I and IV	14b		No
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? If "Yes," complete Schedule F, Parts II and IV	15		No
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? If "Yes," complete Schedule F, Parts III and IV	16		No
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? If "Yes," complete Schedule G, Part I(see instructions)	17		No
18	Did the organization report more than \$15,000 total of fundraising event gross income and contributions on Part VIII, lines 1c and 8a? If "Yes," complete Schedule G, Part II	18	Yes	
19	Did the organization report more than \$15,000 of gross income from gaming activities on Part VIII, line 9a? If "Yes," complete Schedule G, Part III	19		No
20a	Did the organization operate one or more hospital facilities? If "Yes," complete Schedule H	20a		No
Ь	If "Yes" to line 20a, did the organization attach a copy of its audited financial statements to this return?	20b		_
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? If "Yes," complete Schedule I, Parts I and II	21	Yes	
22	Did the expansation report more than 45,000 of grants or other assistance to or for demostic individuals on Bort IV			

government on Part IX, column (A), line 1º If "Yes," complete Schedule I, Parts I and II 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? If "Yes," complete Schedule I, Parts I and III

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Form	990 (2018)			Page 4
Pai	tiV Checklist of Required Schedules (continued)			
			Yes	No
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? If "Yes," complete Schedule J	23	Yes	
24a	Did the organization have a tax-exempt bond issue with an outstanding principal amount of more than \$100,000 as of the last day of the year, that was issued after December 31, 2002? If "Yes," answer lines 24b through 24d and complete Schedule K If "No," go to line 25a	24a		No
b	Did the organization invest any proceeds of tax-exempt bonds beyond a temporary period exception?	24b		
c	Did the organization maintain an escrow account other than a refunding escrow at any time during the year to defease any tax-exempt bonds?	24c		
d	Did the organization act as an "on behalf of" issuer for bonds outstanding at any time during the year?	24d		
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? If "Yes," complete Schedule L, Part I	25a		No
b	Is the organization aware that it engaged in an excess benefit transaction with a disqualified person in a prior year, and that the transaction has not been reported on any of the organization's prior Forms 990 or 990-EZ? If "Yes," complete Schedule L, Part I	25b		No
26	Did the organization report any amount on Part X, line 5, 6, or 22 for receivables from or payables to any current or former officers, directors, trustees, key employees, highest compensated employees, or disqualified persons? If "Yes," complete Schedule L, Part II	26		No
27	Did the organization provide a grant or other assistance to an officer, director, trustee, key employee, substantial contributor or employee thereof, a grant selection committee member, or to a 35% controlled entity or family member of any of these persons? If "Yes," complete Schedule L, Part III	27		No
28	Was the organization a party to a business transaction with one of the following parties (see Schedule L, Part IV instructions for applicable filing thresholds, conditions, and exceptions)			
а	A current or former officer, director, trustee, or key employee? If "Yes," complete Schedule L, Part IV	28a		No
b	A family member of a current or former officer, director, trustee, or key employee? If "Yes," complete Schedule L, Part IV	28b		No
c	An entity of which a current or former officer, director, trustee, or key employee (or a family member thereof) was an officer, director, trustee, or direct or indirect owner? <i>If "Yes," complete Schedule L, Part IV</i>	28c		No
29	Did the organization receive more than \$25,000 in non-cash contributions? If "Yes," complete Schedule M	29		No
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>	30		No
31	Did the organization liquidate, terminate, or dissolve and cease operations? If "Yes," complete Schedule N, Part I .	31		No
32	Did the organization sell, exchange, dispose of, or transfer more than 25% of its net assets? If "Yes," complete Schedule N, Part II	32		No
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? If "Yes," complete Schedule R, Part I	33		No
34	Was the organization related to any tax-exempt or taxable entity? If "Yes," complete Schedule R, Part II, III, or IV, and Part V, line 1	34		No
35a	Did the organization have a controlled entity within the meaning of section 512(b)(13)?	35a		No
b	If 'Yes' to line 35a, did the organization receive any payment from or engage in any transaction with a controlled entity within the meaning of section 512(b)(13)? If "Yes," complete Schedule R, Part V, line 2	35b		
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>	36		No
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? If "Yes," complete Schedule R, Part VI	37		No
38	Did the organization complete Schedule O and provide explanations in Schedule O for Part VI, lines 11b and 197 Note. All Form 990 filers are required to complete Schedule O	38	Yes	
Pa	tV Statements Regarding Other IRS Filings and Tax Compliance			

Yes

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2

0

1a

1b

No

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

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 in line 1a Enter -0- if not applicable

	solicit any contributions that were not tax deductible as charitable contributions?		
b	If "Yes," did the organization include with every solicitation an express statement that such contributions or gifts were not tax deductible?	6b	
7	Organizations that may receive deductible contributions under section 170(c).		
а	Did the organization receive a payment in excess of \$75 made partly as a contribution and partly for goods and services provided to the payor?	7a	No
b	If "Yes," did the organization notify the donor of the value of the goods or services provided?	7 b	
C	Did the organization sell, exchange, or otherwise dispose of tangible personal property for which it was required to file Form 8282?	7 c	No
d	If "Yes," indicate the number of Forms 8282 filed during the year		
e	Did the organization receive any funds, directly or indirectly, to pay premiums on a personal benefit contract?	7e	

10b

11a

11b

12b

13b

13c

12a

13a

14a

14b

15

No

No

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b Gross receipts, included on Form 990, Part VIII, line 12, for public use of club facilities

Gross income from other sources (Do not net amounts due or paid to other sources

b If "Yes," enter the amount of tax-exempt interest received or accrued during the year

a Is the organization licensed to issue qualified health plans in more than one state?

which the organization is licensed to issue qualified health plans

Enter the amount of reserves the organization is required to maintain by the states in

Section 501(c)(29) qualified nonprofit health insurance issuers.

12a Section 4947(a)(1) non-exempt charitable trusts. Is the organization filing Form 990 in lieu of Form 1041?

Note. See the instructions for additional information the organization must report on Schedule O

14a Did the organization receive any payments for indoor tanning services during the tax year?

b If "Yes," has it filed a Form 720 to report these payments? If "No," provide an explanation in Schedule O.

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 instructions and file Form 4720, Schedule N

Is the organization an educational institution subject to the section 4968 excise tax on net investment income?

11 Section 501(c)(12) organizations. Enter a Gross income from members or shareholders .

c Enter the amount of reserves on hand .

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Pai	Governance, Management, and Disclosure For each "Yes" response to lines 2 to 8a, 8b, or 10b below, describe the circumstances, processes, or changes in Schedu Check if Schedule O contains a response or note to any line in this Part VI	ıle O	See ins	tructions		•		lines 🗸
Se	ction A. Governing Body and Management							
							Yes	No
1a	Enter the number of voting members of the governing body at the end of the tax year	1a			14			
	If there are material differences in voting rights among members of the governing body, or if the governing body delegated broad authority to an executive committee or similar committee, explain in Schedule O							
b	Enter the number of voting members included in line 1a, above, who are independent	1b			13			
2	Did any officer, director, trustee, or key employee have a family relationship or a business officer, director, trustee, or key employee?			with any	other	2		No
3	Did the organization delegate control over management duties customarily performed by of officers, directors or trustees, or key employees to a management company or other performance.			dırect su	pervisior	3		No
4	Did the organization make any significant changes to its governing documents since the p	rior F	orm 99	0 was file	ed? .	4		No
5	Did the organization become aware during the year of a significant diversion of the organi	ızatıo	n's asse	ts? .		5		No
6	Did the organization have members or stockholders?					6	Yes	
7a	Did the organization have members, stockholders, or other persons who had the power to members of the governing body?				or more	7a		No
b	Are any governance decisions of the organization reserved to (or subject to approval by)					7b		No

2	officer, director, trustee, or key employee?	2		No
3	Did the organization delegate control over management duties customarily performed by or under the direct supervision of officers, directors or trustees, or key employees to a management company or other person? •	3		No
4	Did the organization make any significant changes to its governing documents since the prior Form 990 was filed? .	4		No
5	Did the organization become aware during the year of a significant diversion of the organization's assets? .	5		No
6	Did the organization have members or stockholders?	6	Yes	
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		No
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		No
8	Did the organization contemporaneously document the meetings held or written actions undertaken during the year by the following			
а	The governing body?	8a	Yes	
ь	Each committee with authority to act on behalf of the governing body?	8b	Yes	
9	Is there any officer, director, trustee, or key employee listed in Part VII, Section A, who cannot be reached at the organization's mailing address? If "Yes," provide the names and addresses in Schedule O	9		No
Se	ction B. Policies (This Section B requests information about policies not required by the Internal Revenue	e Code	∍.)	
			Yes	No
10a	Did the organization have local chapters, branches, or affiliates?	10a		No
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	44-		NI-

5	Did the organization become aware during the year of a significant diversion of the organization's assets? .	5		No
6	Did the organization have members or stockholders?	6	Yes	
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		No
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		No
8	Did the organization contemporaneously document the meetings held or written actions undertaken during the year by the following			
а	The governing body?	8a	Yes	,
Ь	Each committee with authority to act on behalf of the governing body?	8b	Yes	
9	Is there any officer, director, trustee, or key employee listed in Part VII, Section A, who cannot be reached at the organization's mailing address? If "Yes," provide the names and addresses in Schedule O	9		No
Se	ction B. Policies (This Section B requests information about policies not required by the Internal Revenue	e Code	e.)	
			Yes	No
10a	Did the organization have local chapters, branches, or affiliates?	10a		No
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		No
b	Describe in Schedule O the process, if any, used by the organization to review this Form 990			
12a	Did the organization have a written conflict of interest policy? If "No," go to line 13	12a	Yes	
b	Were officers, directors, or trustees, and key employees required to disclose annually interests that could give rise to conflicts?	12b	Yes	
С	Did the organization regularly and consistently monitor and enforce compliance with the policy? <i>If "Yes," describe in Schedule O how this was done</i>	12c	Yes	
13	Did the organization have a written whistleblower policy?	13	Yes	
14	Did the organization have a written document retention and destruction policy?	14	Yes	
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?			
а	The organization's CEO, Executive Director, or top management official	15a	Yes	
Ь	Other officers or key employees of the organization	15b		No
	If "Yes" to line 15a or 15b, describe the process in Schedule O (see instructions)			
16a	Did the organization invest in, contribute assets to, or participate in a joint venture or similar arrangement with a taxable entity during the year?	16a		No
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			

а	The governing body?	8a	Yes	
b	Each committee with authority to act on behalf of the governing body?	8 b	Yes	
9	Is there any officer, director, trustee, or key employee listed in Part VII, Section A, who cannot be reached at the organization's mailing address? If "Yes," provide the names and addresses in Schedule O	9		No
Se	ction B. Policies (This Section B requests information about policies not required by the Internal Revenue	e Code	·.)	
			Yes	No
10a	Did the organization have local chapters, branches, or affiliates?	10a		No
ь	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		No
b	Describe in Schedule O the process, if any, used by the organization to review this Form 990			
12a	Did the organization have a written conflict of interest policy? If "No," go to line 13	12a	Yes	
Ь	Were officers, directors, or trustees, and key employees required to disclose annually interests that could give rise to conflicts?	12b	Yes	
c	Did the organization regularly and consistently monitor and enforce compliance with the policy? If "Yes," describe in Schedule O how this was done	12c	Yes	
13	Did the organization have a written whistleblower policy?	13	Yes	
14	Did the organization have a written document retention and destruction policy?	14	Yes	
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?			_
а	The organization's CEO, Executive Director, or top management official	15a	Yes	
b	Other officers or key employees of the organization	15b		No
	If "Yes" to line 15a or 15b, describe the process in Schedule O (see instructions)			
16a	Did the organization invest in, contribute assets to, or participate in a joint venture or similar arrangement with a taxable entity during the year?	16a		No
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		
-	ction C. Disclosure			
17	List the States with which a copy of this Form 990 is required to be filed AK , AR , CA , CO , CT , DC , FL , GA , IL , MA , MI , MN , MS , NH , NJ , NM , NY , NC RI , SC , TN , UT , VT , VA , WA , WV , WI			
18	Section 6104 requires an organization to make its Form 1023 (or 1024-A if applicable), 990, and 990-T (501(c)(3)s only) available for public inspection. Indicate how you made these available.			
	☑ Own website ☐ Another's website ☑ Upon request ☐ Other (explain in Schedule O)			

Describe in Schedule O whether (and if so, how) the organization made its governing documents, conflict of interest policy, and financial statements available to the public during the tax year

State the name, address, and telephone number of the person who possesses the organization's books and records THE FOUNDATION 804 W DIAMOND AVE SUITE 210 GAITHERSBURG, MD 20878 (301) 947-0083

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
- List all of the organization's current officers, directors, trustees (whether individuals or organizations), regardless of amount of compensation Enter -0- in columns (D), (E), and (F) if no compensation was paid
- List all of the organization's current key employees, if any See instructions for definition of "key employee" • List the organization's five current highest compensated employees (other than an officer, director, trustee or key employee)
- who received reportable compensation (Box 5 of Form W-2 and/or Box 7 of Form 1099-MISC) of more than \$100,000 from the organization and any related organizations • List all of the organization's former officers, key employees, or highest compensated employees who received more than \$100,000
- of reportable compensation from the organization and any related organizations • List all of the organization's former directors or trustees that received, in the capacity as a former director or trustee of the
- organization, more than \$10,000 of reportable compensation from the organization and any related organizations List persons in the following order individual trustees or directors, institutional trustees, officers, key employees, highest compensated employees, and former such persons

compensated employees, and former such person Check this box if neither the organization no		ganızal	ion c	omp	ens	ated a	ny c	current officer, dire	ctor, or trustee	
(A) Name and Title	(B) Average hours per week (list any hours for related	Position than o	on (de one be	(C o no ox, u n of tor/t) t ch unle: ficei rust	eck mess personal and a	ore son	(D) Reportable compensation from the organization (W- 2/1099-	(E) Reportable compensation from related organizations (W- 2/1099-	(F) Estimated amount of other compensation from the
	organizations below dotted line)	Individual trustee or director	Institutional Trustee	Officer	key employee	Highest compensated employee	Former	MISC)	MISC)	organization and related organizations
(1) ERIC GOULD BOARD MEMBER	2 00	x						0	0	0
(2) KENNETH W GUDEK SR PRESIDENT	2 00	Х		х				0	0	0
(3) JOE HALL BOARD MEMBER	2 00	Х						0	0	0
(4) TED TRAHAN TREASURER	2 00	х		×				0	0	0
(5) KARA B AYERS PHD SECRETARY	2 00	х		х				0	0	0
(6) BRETT EISENBERG BOARD MEMBER	2 00	х						0	0	0
(7) SHARON MUTNICK BOARD MEMBER	2 00	х						0	0	0
(8) S JACINTA WHYTE BOARD MEMBER	2 00	х						0	0	0
(9) CHRISTINE ROSSI BOARD MEMBER	2 00	х						0	0	0
(10) MICHELE BURKA BOARD MEMBER	2 00	х						0	0	0
(11) CAMERON R PENN FIRST VICE PRESIDENT	2 00	х		х				0	0	0
(12) FRANCIS GLORIEUX OC MD PHD CHAIRMAN - MEDICAL ADVISORY COMMITTEE	2 00	Х		х				0	0	0
(13) KEN FINKEL BOARD MEMBER	2 00	Х						0	0	0
(14) LAURA TOSI MD BOARD MEMBER	2 00	х						0	0	0
(15) TRACY SMITH HART CHIEF EXECUTIVE OFFICER	40 00				х			183,382	0	30,026
(16) MARCIAL T COSTANZO DIRECTOR OF FINANCE	40 00					х		113,085	0	5,634
										Form 990 (2018)

Form 990 (2018)										Page 8
Part VII Section A. Officers, Dire	ectors, Trustees	s, Key	Emp	loye	es,	and I	High	nest Compensate	d Employees (co	ntinued)
(A) Name and Title	(B) Average hours per week (list any hours	(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-	(E) Reportable compensation from related organizations (W-	(F) Estimated amount of other compensation from the
	for related organizations below dotted line)	Individual trustee or director	Institutional Trustee	Officer	Key employee	Highest compensated employee	Former	2/1099-MISC)	Ž/1099-MISĊ)	organization and related organizations

	-	4) वास्त		

1b Sub-Total	b Sub-Total											
c Total from continuation sheets to Part VII, Section A ▶												
d Total (add lines 1b and 1c)						>		296,467	0			
2 Total number of individuals (including			e liste	ed al	bove	e) who	rece	eived more than	\$100,000			

	Total (add lines 1b and 1c)	0		35,660
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 \triangleright 2			
			Yes	No
3	Did the organization list any former officer, director or trustee, key employee, or highest compensated employee on line 1a? <i>If "Yes," complete Schedule J for such individual</i>	3		No
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? If "Yes," complete Schedule J for such			
	ındıvıdual	4	Yes	

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 \triangleright 2			
		Ye	s	No
3	Did the organization list any former officer, director or trustee, key employee, or highest compensated employee on line 1a? If "Yes," complete Schedule J for such individual			No
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? If "Yes," complete Schedule J for such individual	Ye	5	
_	<u>-</u>	+ '	"	

			Yes	No					
3	Did the organization list any former officer, director or trustee, key employee, or highest compensated employee on line 1a? <i>If "Yes," complete Schedule J for such individual</i>	3		No					
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? If "Yes," complete Schedule J for such individual	4	Yes						
5	Did any person listed on line 1a receive or accrue compensation from any unrelated organization or individual for services rendered to the organization? If "Yes," complete Schedule J for such person	5		No					
Se	Section B. Independent Contractors								

		ا د		NO				
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? If "Yes," complete Schedule J for such individual	4	Yes					
5	Did any person listed on line 1a receive or accrue compensation from any unrelated organization or individual for services rendered to the organization? If "Yes," complete Schedule J for such person	5		No				
Se	Section B. Independent Contractors							

	organization and related organizations greater than \$150,000? If "Yes," complete Schedule J for such								
	ındıvıdual	4	Yes						
5	Did any person listed on line 1a receive or accrue compensation from any unrelated organization or individual for services rendered to the organization? If "Yes," complete Schedule J for such person								
Se									
1	Complete this table for your five highest compensated independent contractors that received more than \$100,000 of compensation								

	· · · · · · · · · · · · · · · · · · ·	-	162					
5	Did any person listed on line 1a receive or accrue compensation from any unrelated organization or individual for services rendered to the organization? If "Yes," complete Schedule J for such person	5		No				
S	Section B. Independent Contractors							
1	Complete this table for your five highest compensated independent contractors that received more than \$100,000 of compensation							

5 Did any person listed on line 1a receive or accrue compensation from any unrelated organization or individual for services rendered to the organization? If "Yes," complete Schedule J for such person				No				
Se	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							

	5		No					
S	ection 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)	ation			

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				

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				
4-	•		Form 000 (2019)	

	90 (2018)						Page 9
Part				cline in this Dest VIII			
	Check if Schedule O contains	a respo	onse or note to any	(A) Total revenue	(B) Related or exempt function	(C) Unrelated business revenue	(D) Revenue excluded from tax under sections
	1a Federated campaigns	1a	4,664		revenue		512 - 514
ints ints	b Membership dues	1b	27,559				
Gra	c Fundraising events	1c	493,093				
£, ₹	d Related organizations	1d					
<u>ה</u>	e Government grants (contributions)	1e	87,597				
Contributions, Gifts, Grants and Other Similar Amounts	f All other contributions, gifts, grants, and similar amounts not included		1.046.210				
ř ř	above	1f	1,046,318				
	g Noncash contributions included in lines 1a - 1f \$	4,6	511				
Cont and I	h Total. Add lines 1a-1f		▶	1,659,231			
ı			Busines				
พา	2a	_					
æ	b	_					
A V	c	_					
3	d	_					
ranı	f All other program service revenue						
Program Service Revenue	9Total. Add lines 2a-2f		_				
	3 Investment income (including divid		nterest, and other	1	1		
	sımılar amounts)		1	42,95	2		42,952
	4 Income from investment of tax-exe			<u> </u>	1		
	5 Royalties		(II) Personal	<u> </u>			
	6a Gross rents		,				
	b Less rental expenses			_			
				_			
	c Rental income or (loss)						
	d Net rental income or (loss)	•		<u>]</u>			
	(i) Securit	ties	(II) Other	_			
	7a Gross amount from sales of assets other	356,949					
	than inventory						
		222,718					
	sales expenses C Gain or (loss)	.34,231		-			
	d Net gain or (loss)	•	•	134,23	1		134,231
	8a Gross income from fundraising ev						
Other Revenue	(not including \$ 493,093 contributions reported on line 1c)						
eve	See Part IV, line 18		204,250	_			
ت ه	b Less direct expensesc Net income or (loss) from fundrais	b sina ev	·		0		
the	9a Gross income from gaming activit						
0	See Part IV, line 19	a					
	b Less direct expenses	b		_			
	c Net income or (loss) from gaming	actıvıt	les >				
	10a Gross sales of inventory, less returns and allowances						
	retains and anomances i	а	J 3,187	7			
	${f b}$ Less cost of goods sold	b	4,260				
	c Net income or (loss) from sales of	invent		-1,07	3 -1,073	3	
	Miscellaneous Revenue		Business Code	_			
	-						
	b						
	с				1		
	d All other revenue						
	e Total. Add lines 11a-11d						
	12 Total revenue. See Instructions			1,835,34	1 -1,073		0 177,183
				, , , , , ,		•	Form 990 (2018)

Check here ▶ ☑ If following SOP 98-2 (ASC 958-720)

Form 990 (2018)				Page 10
Part IX Statement of Functional Expenses Section 501(c)(3) and 501(c)(4) organizations must complete all co	olumns All other orga	unizations must comm	lete column (A)	
Check if Schedule O contains a response or note to any	-	·	, ,	🗆
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) Fundraisingexpenses
Grants and other assistance to domestic organizations and domestic governments See Part IV, line 21	279,342	279,342	general expenses	
2 Grants and other assistance to domestic individuals See Part IV, line 22	85,490	85,490		
3 Grants and other assistance to foreign organizations, foreign governments, and foreign individuals. See Part IV, line 15 and 16.				
4 Benefits paid to or for members				
5 Compensation of current officers, directors, trustees, and key employees	218,703	185,905	28,220	4,578
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	622,706	281,905	225,024	115,777
8 Pension plan accruals and contributions (include section 401 (k) and 403(b) employer contributions)	17,742	7,942	5,965	3,835
9 Other employee benefits	45,868	28,013		17,855
10 Payroll taxes	59,590	31,953	18,079	9,558
11 Fees for services (non-employees)				
a Management				
b Legal				
c Accounting	34,235		34,235	
d Lobbying				
e Professional fundraising services See Part IV, line 17				
f Investment management fees	42,729		42,697	32
g Other (If line 11g amount exceeds 10% of line 25, column (A) amount, list line 11g expenses on Schedule O)	30,831	25,260	1,823	3,748
12 Advertising and promotion				
13 Office expenses	57,262	29,475	10,029	17,758
14 Information technology	63,272	52,151	7,180	3,941
-· <u>-</u> -·	03,272	32,131	7,100	3,541
15 Royalties	78.919	42,659	24,733	11.527
16 Occupancy		,	· · · · · · · · · · · · · · · · · · ·	
17 Travel	19,518	2,774	223	16,521
18 Payments of travel or entertainment expenses for any federal, state, or local public officials			5.0.0	
19 Conferences, conventions, and meetings	393,324	387,690	5,319	315
20 Interest	7,040		7,040	
21 Payments to affiliates				
22 Depreciation, depletion, and amortization	11,506	6,219	3,606	1,681
23 Insurance	7,763	2,262	1,380	4,121
24 Other expenses Itemize expenses not covered above (List miscellaneous expenses in line 24e If line 24e amount exceeds 10% of line 25, column (A) amount, list line 24e				
expenses on Schedule O) a SURVEY	9,836	9,836		
b research	8,500	8,500		
c LICENSE AND PERMITS	8,029	51	29	7,949
d MISCELLANEOUS	3,000		3,000	
		1511		
e All other expenses	4,545	4,511	23	210 207
25 Total functional expenses. Add lines 1 through 24e 26 Joint costs. Complete this line only if the organization reported in column (B) joint costs from a combined educational campaign and fundraising solicitation	2,109,750	1,471,938	418,605	219,207
Check here				

Pa	art X	Balance Sheet					
		Check if Schedule O contains a response or not	e to ar	ny line in this Part IX			<u> </u>
					(A) Beginning of year		(B) End of year
	1	Cash-non-interest-bearing			257,736	1	29,303
	2	Savings and temporary cash investments			131,252	2	118,528
	3	Pledges and grants receivable, net	230,652	3	101,119		
	4	Accounts receivable, net			135,577	4	60,167
	5 6	Loans and other receivables from current and for trustees, key employees, and highest compensa Part II of Schedule L Loans and other receivables from other disquality		5			
ts	_	section 4958(f)(1)), persons described in sectio contributing employers and sponsoring organiza- voluntary employees' beneficiary organizations Part II of Schedule L		6			
Assets	7	Notes and loans receivable, net			10 044		42.242
As	8	Inventories for sale or use			16,811	8	13,212
,	9	Prepaid expenses and deferred charges			49,398	9	35,514
	10a	Land, buildings, and equipment cost or other basis Complete Part VI of Schedule D	10a	159,418			
	b	Less accumulated depreciation	10 b	122,478	22,846	10 c	36,940
	11	Investments—publicly traded securities .			1,420,941	11	1,348,450
	12	Investments—other securities See Part IV, line 11				12	
	13					13	
	14	Intangible assets				14	
	15	Other assets See Part IV, line 11			22,262	15	25,025

2.287.475

75,402

239,500

117.805

15.289

447.996

795.225

1,005,266

1,839,479

2,287,475

38.988

16

17

18

19

20

21

22

23

24

25

26

27

28

29

30

31 32

33

34

1.768.258

95.526

161.826

14.145

0

58

271.555

782.895

713.808

1,496,703

1,768,258

Form **990** (2018)

16

17

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34

Liabilities 22

Fund Balances

Assets or 30

Net

Total assets. Add lines 1 through 15 (must equal line 34) . . .

Escrow or custodial account liability Complete Part IV of Schedule D

key employees, highest compensated employees, and disqualified

Secured mortgages and notes payable to unrelated third parties

Unsecured notes and loans payable to unrelated third parties

complete lines 27 through 29, and lines 33 and 34.

Organizations that do not follow SFAS 117 (ASC 958), check here > and complete lines 30 through 34.

Capital stock or trust principal, or current funds

Paid-in or capital surplus, or land, building or equipment fund .

Retained earnings, endowment, accumulated income, or other funds

Loans and other payables to current and former officers, directors, trustees,

Other liabilities (including federal income tax, payables to related third parties,

Organizations that follow SFAS 117 (ASC 958), check here 🕨 🗹 and

Accounts payable and accrued expenses

Tax-exempt bond liabilities . . .

persons Complete Part II of Schedule L .

and other liabilities not included on lines 17 - 24)

Total liabilities. Add lines 17 through 25 .

Grants payable . .

Deferred revenue . . .

Complete Part X of Schedule D

Temporarily restricted net assets

Permanently restricted net assets

Total net assets or fund balances

Total liabilities and net assets/fund balances

Unrestricted net assets

Audit Act and OMB Circular A-133? 3a No

b If "Yes," did the organization undergo the required audit or audits? If the organization did not undergo the required audit or audits, explain why in Schedule O and describe any steps taken to undergo such audits 3b Form 990 (2018)

Additional Data

Software ID:

Software Version:

EIN: 23-7076021

Name: OSTEOGENESIS IMPERFECTA FOUNDATION INC

Form 990 (2018)

Form 990, Part III, Line 4a:

THE FOUNDATION FUNDS GRANTS TO SUPPORT RESEARCH RELEVANT TO UNDERSTANDING AND TREATING OI. THROUGH THE MICHAEL GEISMAN FELLOWSHIP PROGRAM. OIF'S YOUNG INVESTIGATOR GRANT PROGRAM NAMED FOR THE SON OF OIF FOUNDER, GEMMA GEISMAN, FELLOWSHIPS ARE AWARDED TO POST-DOCTORAL TRAINEES WORKING ON PROJECTS WITH CLEAR RELEVANCE TO OI THIS PAST YEAR, OIF AWARDED FIRST YEAR FUNDING TO DR HEESEOG KANG FROM THE NATIONAL INSTITUTES OF HEALTH, NIAMS DR KANG'S RESEARCH WAS TITLED PEDF-PARY-CYCLOPHILINA/B PATHWAY MODULATES OSTEOGENESIS IMPERFECTA OIF HOSTS AN ANNUAL SCIENTIFIC MEETING TO BRING TOGETHER LEADERS IN CLINICAL AND BASIC RESEARCH ON A SINGLE TOPIC RELATED TO OI IN ADDITION, THE FOUNDATION PARTICIPATES IN NUMEROUS RESEARCH MEETINGS SPONSORED BY OTHER ORGANIZATIONS, INCLUDING THE NATIONAL INSTITUTES OF HEALTH (NIH) EVERY THIRD YEAR, OIF JOINS OTHER OI ASSOCIATIONS AT THE INTERNATIONAL SCIENTIFIC CONGRESS ON OI A KEY ACTIVITY FOR THE FOUNDATION CONTINUES TO BE THE PARTICIPATION IN THE BRITTLE BONE DISORDERS CONSORTIUM (BBDC) OIF IS RESPONSIBLE FOR PROVIDING EDUCATION TO MEDICAL PROFESSIONALS THROUGH MATERIALS AND MEETINGS DESIGNED TO GIVE THE MOST UP-TO-DATE INFORMATION ON OI CARE AND RESEARCH. THROUGH THE SUPPORT OF THE FOUNDATION, SUPPORTED LINKED CLINICAL RESEARCH CENTERS (LCRC), AND CONSTITUENT PARTICIPATION, OIF WAS ABLE TO GATHER IMPORTANT INFORMATION ABOUT INDIVIDUALS LIVING WITH OI AND FORM THE FOUNDATION ON WHICH THE BBDC WAS BUILT. THIS IS THE ONLY RARE DISEASE NETWORK AT THE NIH THAT IS STUDYING BONE AND SPECIFICALLY OI UNDER THE LEADERSHIP OF OIF MEDICAL ADVISORY COUNCIL MEMBER, DR BRENDAN LEE OF BAYLOR COLLEGE OF MEDICINE THE BBDC HAS COMPLETED SEVEN STUDIES AND HAS SEVERAL MORE IN PROGRESS MORE THAN 1,500 PEOPLE HAVE JOINED THE BBDC CONTACT REGISTRY AND THE CONSORTIUM CONTINUES TO WORK WITH ITS PARTNERS INCLUDING TAMPA SHRINERS HOSPITAL FOR CHILDREN, A I DUPONT HOSPITAL FOR CHILDREN, COLOGNE HOSPITAL IN COLOGNE, GERMANY, BAYLOR COLLEGE OF MEDICINE, MONTREAL SHRINERS HOSPITALS FOR CHILDREN, CHICAGO SHRINERS HOSPITALS FOR CHILDREN, KENNEDY KREIGER INSTITUTE, HOSPITAL FOR SPECIAL SURGERY, OREGON HEALTH AND SCIENCE UNIVERSITY AND NATIONAL CHILDREN'S MEDICAL CENTER. THE CLINICAL RESEARCH IN PROGRESS INCLUDES A PHASE I DRUG STUDY, A STUDY ON SCOLIOSIS IN PEOPLE WITH SEVERE OI, PREGNANCY AND OI, DENTINOGENESIS IMPERFECTA AND OTHER DENTAL/CRANIOFACIAL ISSUES AND OI. A BIOMARKERS STUDY. AND A QUALITY OF LIFE AND OI STUDY OIF CONTINUES TO IMPROVE ITS WEB BASED "TOOL KIT" CALLED THE INFORMATION FOR MEDICAL PROFESSIONALS, WHICH WAS DEVELOPED AS PART OF THE BBDC. THE INFORMATION CENTER, LOCATED AT WWW OIF ORG/MEDED, COVERS INFORMATION ABOUT OI, BOTH ISSUES THAT AFFECT CHILDREN AND ADULTS, AND PROVIDES ONLINE RESOURCES FOR PROVIDERS WHO SEE FEW OI PATIENTS THE SITE IS ALSO HOST TO OIF PODCASTS (20 TO DATE) ON A VARIETY OF TOPICS INCLUDING SPINE ISSUES AND BASILAR INVAGINATION IN OI, DENTAL, SURGICAL INTERVENTIONS, PREGNANCY AND OI, HEARING LOSS AND OI, MENTAL HEALTH AND THE OI PATIENT, TREATMENT OPTIONS FOR ADULTS AND CHILDREN AND AN OVERVIEW OF THE DIAGNOSIS AND TREATMENT OF OI THE PODCASTS HAVE BEEN DOWNLOADED A TOTAL OF 1,609 TIMES DURING CALENDAR YEAR 2019, AND ARE A VERY POPULAR FEATURE OF OIF'S MEDICAL PROFESSIONAL EDUCATIONAL OUTREACH

Form 990, Part III, Line 4b:

VOLUNTEER RESOURCE PEOPLE ARE ACTIVE IN 25 STATES

PHONE, INTERNET, FAX, SOCIAL MEDIA AND MAIL EDUCATIONAL MATERIALS ARE AVAILABLE IN PRINT AND ELECTRONICALLY THROUGH THE OIF WEBSITE PRINT MATERIALS INCLUDE BOOKS, BROCHURES, FACT SHEETS AND A QUARTERLY NEWSLETTER ELECTRONIC MATERIALS INCLUDE A MONTHLY EMAIL NEWSLETTER, AND VIA

THE WEBSITE, FACT SHEETS, BOOKLETS AND BROCHURES INFORMATION ON OI IS WRITTEN FOR A VARIETY OF AUDIENCES INCLUDING MEDICAL PROFESSIONALS, PARENTS AND OTHER FAMILY MEMBERS, CHILDREN, ADULTS WHO HAVE OI, AND SCHOOL PROFESSIONALS ON AVERAGE, 40,000 PEOPLE USE THE WEBSITE EACH

MONTH FOUNDATION STAFF AND VOLUNTEERS RESPOND TO MORE THAN 7.500 DIRECT INQUIRIES A YEAR INFORMATION FROM THESE CONTACTS IS USED TO ASSESS THE NEED FOR NEW RESOURCES. THE FOUNDATION SPONSORS A NETWORK OF SUPPORT GROUPS ACROSS THE UNITED STATES. SUPPORT GROUP ACTIVITIES PROVIDE

THE FOUNDATION OFFERS MEDICALLY VERIFIED INFORMATION RELATED TO 01 TOPICS INCLUDE MEDICAL ISSUES SUCH AS GENETICS, DIAGNOSIS AND TREATMENTS ADDITIONAL TOPICS FOCUS ON DAILY LIVING STRATEGIES, SCHOOL AND EMPLOYMENT THE FOUNDATION'S STAFF REPLIES TO REQUESTS FOR INFORMATION VIA

OPPORTUNITIES FOR MUTUAL SUPPORT AND INCREASED COMMUNITY AWARENESS CURRENTLY, THERE ARE 38 ACTIVE GROUPS IN 32 STATES IN ADDITION, 26

OIF STRIVES TO BUILD PUBLIC AWARENESS AND GENERATE ADDITIONAL SUPPORT AMONG PEOPLE WITH OI, COMMUNITY ORGANIZATIONS, GOVERNMENT AGENCIES, THE PUBLIC, SCHOOL PERSONNEL AND MEDICAL PROFESSIONALS THE FOUNDATION HAS A PUBLIC SERVICE ANNOUNCEMENT, AND PARTNERS WITH RELATED

Form 990, Part III, Line 4c:

EUROPE IN ADDITION, OIF PARTICIPATES IN RARE DISEASE DAY ACTIVITIES, AND SPONSORS OI AWARENESS WEEK EACH MAY NATIONAL OSTEOGENESIS IMPERFECTA AWARENESS WEEK 2019 WAS MAY 4-11, 2019 VOLUNTEERS PROCLAIMED OI AWARENESS WEEK IN OVER 13 CITIES AND STATES, AND HELD MULTIPLE EVENTS NATIONWIDE OIF CELEBRATED WISHBONE DAY, THE INTERNATIONAL OI AWARENESS DAY, BY SHARING FACTS AND INFORMATION VIA SOCIAL MEDIA EVERY HOUR FOR

ORGANIZATIONS SUCH AS THE U.S. BONE & JOINT DECADE, THE NATIONAL ORGANIZATION FOR RARE DISORDERS, THE NATIONAL BONE HEALTH ALLIANCE. THE RARE DISEASE PATIENT NETWORK, THE NATIONAL HEALTH COUNCIL, COMMITTEES/COUNCILS OF THE NATIONAL INSTITUTES OF HEALTH, AND THE OI FEDERATION OF

A CONSECUTIVE TWELVE HOURS DURING OI AWARENESS WEEK 2019. OIF REACHED MORE THAN 200,000 PEOPLE ON FACEBOOK AND GAINED MORE THAN 100 NEW

FACEBOOK FOLLOWERS OIF MANAGES FOUR SOCIAL NETWORKING SITES AND CONTINUES TO OFFER. THROUGH ITS WEBSITE WWW OIF ORG. LINKS TO SITES THAT MIGHT BE HELPFUL OR INTERESTING TO PARENTS AND YOUNG PEOPLE LIVING WITH OI. IN ADDITION TO SITES THAT HELP OLDER ADULTS WITH OI MANAGE THEIR DISORDER THROUGHOUT THEIR LIFE THROUGH MUTUAL SUPPORT. THE FOUNDATION ALSO MAINTAINS AN OFFICIAL DIE FACEBOOK PAGE THAT PROVIDES INFORMATION

AND RESOURCES TO ALL AGES AND IS UPDATED DAILY CURRENTLY, THE OIF FACEBOOK PAGE HAS 12,429 FOLLOWERS THE FOUNDATION IS COMMITTED TO

ADVOCATING ON BEHALF OF PEOPLE WITH OI OIF HAS ESTABLISHED AN ADVOCACY INITIATIVE. A GRASSROOTS EFFORT FOCUSING ON EDUCATING LEGISLATORS AND

THEIR STAFE ABOUT OF AND THE PRIORITIES OF THE FOUNDATION

SCHEDULE A (Form 990 or 990EZ)			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 the latest information.				a section	2018 Open to Public
epartment of th ternal Revenue ame of the	Service	ion		www.msiqov/romm.	<u> </u>		Employer identific	Inspection
STEOGENESIS	IMPERFECTA	FOUNDATION	INC				23-7076021	
				us (All organization				
-		•		e it is (For lines 1 thro	•			
L	church, co	nvention of	churches, or as	sociation of churches	described in sec	tion 170(b)(1)	(A)(i).	
2 🗆 A	school de	scribed in se	ction 170(b)(1)(A)(ii). (Attach Sch	nedule E (Form 9	990 or 990-EZ))		
· 🗆 A	hospital o	r a cooperati	ve hospital ser	vice organization desci	rıbed ın section	170(b)(1)(A)(iii).	
	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							
	-	tion operated iv). (Comple		t of a college or unive	rsity owned or o	perated by a gov	ernmental unit descri	bed in section 170
			•	governmental unit de	scribed in secti	on 170(b)(1)(A	\)(v).	
			mally receives (vi). (Complete	a substantial part of it Part II)	s support from a	a governmental u	ınıt or from the gener	al public described ii
3 🗆 A	communit	y trust descr	ibed in sectio i	170(b)(1)(A)(vi)	(Complete Part I	Π)		
				escribed in 170(b)(1) ee instructions Enter				lege or university or
f II	rom activiti nvestment	es related to income and i	ıts exempt fur unrelated busır	(1) more than 331/39 actions—subject to cer- less taxable income (le amplete Part III)	taın exceptions,	and (2) no more	than 331/3% of its s	upport from gross
				d exclusively to test fo	r public safety	See section 509	(a)(4).	
r	nore public	ly supported	organizations	d exclusively for the be described in section 5 the type of supporting	09(a)(1) or se	ction 509(a)(2). See section 509(a	
י ו	ype I. A s organization	upporting org	ganızatıon oper	ated, supervised, or co	ontrolled by its s	supported organiz	zation(s), typically by	
□ r	nanagemer	it of the supp	- '	ervised or controlled i ation vested in the sar and C.			- ' ' '	~
		•	_	supporting organizatio	•	•	, -	ated with, its
	ype III no unctionally	on-function integrated	ally integrate The organizatio	 d. A supporting organi n generally must satis rt IV, Sections A and 	zation operated fy a distribution	in connection wi requirement and	th its supported orgai	
			•	ved a written determir	•		pe I, Type II, Type II	I functionally
_ "	ntegrated,	or Type III n		integrated supporting		•		,
			on about the si	pported organization(s)			
	me of supp rganization	orted	(ii) EIN (iii) Type of organization listed in your governing document? (described on lines 1- 10 above (see instructions))			(v) Amount of monetary support (see instructions)	(vi) Amount of other support (se instructions)	
					Yes	No		
tal.								
otal	.d. D. d		i +b- T	structions for	Cat No 1128!	<u> </u>	 Schedule A (Form 9	200 57\ 200

instructions

rage	_
170	

oport Schedule for Organizations Described in Sections 170(b)(1)(A)(iv), 170(b)(1)(A)(vi), and 170
(1)(A)(ix)
mplete only if you checked the box on line 5, 7, 8, or 9 of Part I or if the organization failed to qualify under Part
If the organization fails to qualify under the tests listed below, please complete Part III.)

	III. If the organization fai						iy under Part
_	Section A. Public Support	iis to quality ut	ider the tests his	ted below, pied.	se complete rai	C 111.)	
	Calendar year		I	T	T		
	(or fiscal year beginning in) ▶	(a) 2014	(b) 2015	(c) 2016	(d) 2017	(e) 2018	(f) Total
1	Gifts, grants, contributions, and						
	membership fees received (Do not						
	include any "unusual grant ")						
2	Tax revenues levied for the						
	organization's benefit and either paid						
_	to or expended on its behalf The value of services or facilities						
3	furnished by a governmental unit to						
	the organization without charge						
4	Total. Add lines 1 through 3						
5	The portion of total contributions by						
5	each person (other than a						
	governmental unit or publicly						
	supported organization) included on						
	line 1 that exceeds 2% of the amount						
	shown on line 11, column (f)						
6	Public support. Subtract line 5 from						
	line 4						
S	Section B. Total Support						
	Calendar year	(a)2014	(b) 2015	(c)2016	(d)2017	(e)2018	(f)Total
	(or fiscal year beginning in) ▶	(-,	(=,====	(3,2323	(-)	(0)2020	(1).010.
7							
8	Gross income from interest,						
	dividends, payments received on						
	securities loans, rents, royalties and						
_	income from similar sources						
9	Net income from unrelated business						
	activities, whether or not the business is regularly carried on						
10							
10	loss from the sale of capital assets						
	(Explain in Part VI)						
11	Total support. Add lines 7 through						
	10						
12	Gross receipts from related activities, e	tc (see instruction	ons)			12	
13	First five years. If the Form 990 is for	the organization	s first, second, th	urd, fourth, or fifth	n tax vear as a sec	tion 501(c)(3) org	anization.
	check this box and stop here	=				· · · · · · <u>-</u>	_
_	section C. Computation of Public						_
	Public support percentage for 2018 (line			column (f))			
				column (1))		14	
	Public support percentage for 2017 Sch					15	
16 a	33 1/3% support test—2018. If the				ne 14 is 33 1/3% o	r more, check this	box
	and stop here. The organization qualif						··►□
b	33 1/3% support test—2017. If the	organization did	not check a box o	on line 13 or 16a,	and line 15 is 33 i	1/3% or more, chec	k this
	box and stop here. The organization	qualifies as a pub	olicly supported or	ganızatıon			▶□
17 a	10%-facts-and-circumstances test-	–2018. If the or	ganization did not	check a box on lir	ne 13, 16a, or 16b	, and line 14	
	is 10% or more, and if the organization						
	in Part VI how the organization meets t	he "facts-and-cir	cumstances" test	The organization	qualifies as a publ	icly supported	
	organization						▶ □
Į.	10%-facts-and-circumstances test	-2017. If the o	rganization did no	ticheck a box on l	ine 13, 16a, 16h	or 17a, and line	
0	15 is 10% or more, and if the organiza						
	Explain in Part VI how the organization						
	supported organization			5-	4	,	▶□
10	Private foundation. If the organization	n did not check :	hov on line 12 1	6a 16h 17a or 1	7h check this has	and see	F L
TΩ	Trivate roundation, if the organization	ii ala not check e	4 POV OIL HIE TO, T	ou, 100, 1/a, 01 1	. , D, CHECK HIIS DU)	, unu see	

Section A. Public Support

Part III

(or fiscal year beginning in) ▶	(a) 2014	(b) 2015	(c) 2016	(d) 2017	(e) 2018	(f) Total
Gifts, grants, contributions, and membership fees received (Do not include any "unusual grants")	1,612,358	1,263,238	1,532,881	1,485,493	1,659,233	7,553,203
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	8,071	2,404	2,739	2,272	3,187	18,673
3 Gross receipts from activities that are not an unrelated trade or business under section 513	112,824	148,712	192,284	218,234	204,250	876,304
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						

(Complete only if you checked the box on line 10 of Part I or if the organization failed to qualify under Part II. If

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

the organization fails to qualify under the tests listed below, please complete Part II.)

the organization without charge 1,727,904 1,733,253 1,414,354 1,705,999 1,866,670 8,448,180 Total. Add lines 1 through 5 Amounts included on lines 1, 2, and 291,134 410,247 250,820 343,833 319,901 1,615,935

	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				20,038	128,117	148,155
С	Add lines 7a and 7b	291,134	410,247	250,820	363,871	448,018	1,764,090
8	Public support. (Subtract line 7c from line 6)						6,684,090
Se	ction B. Total Support						
	Calendar year (or fiscal year beginning in) ▶	(a) 2014	(b) 2015	(c) 2016	(d) 2017	(e) 2018	(f) Total
9	Amounts from line 6	1,733,253	1,414,354	1,727,904	1,705,999	1,866,670	8,448,180
10a	Gross income from interest, dividends, payments received on securities loans, rents, royalties and income from similar sources	40,090	46,248	37,809	42,137	42,952	209,236
b	Unrelated business taxable income (less section 511 taxes) from businesses acquired after June 30, 1975						
С	Add lines 10a and 10b	40,090	46,248	37,809	42,137	42,952	209,236
11	Net income from unrelated business activities not included in line 10b, whether or not the business is						
12	regularly carried on 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)	1,773,343	1,460,602	1,765,713	1,748,136	1,909,622	8,657,416

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

14

Section C. Computation of Public Support Percentage 15

Public support percentage for 2018 (line 8, column (f) divided by line 13, column (f))

Public support percentage from 2017 Schedule A, Part III, line 15 16

20

Section D. Computation of Investment Income Percentage Investment income percentage for 2018 (line 10c, column (f) divided by line 13, column (f)) 17

Investment income percentage from 2017 Schedule A, Part III, line 17

more than 33 1/3%, check this box and stop here. The organization qualifies as a publicly supported organization

not more than 33 1/3%, check this box and stop here. The organization qualifies as a publicly supported organization

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

19a 331/3% support tests—2018. 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

b 33 1/3% support tests—2017. 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

15

16

17

18

Schedule A (Form 990 or 990-EZ) 2018

2	420	<u>~</u>
77	900	%
77	210	%

_	400	
77	900	%
//	210	%

2 570 %

Schedule A (Form 990 or 990-EZ) 2018 Page 4 Part IV Supporting Organizations (Complete only if you checked a box on line 12 of Part I If you checked 12a of Part I, complete Sections A and B If you checked 12b of

Part I, complete Sections A and C If you checked 12c of Part I, complete Sections A, D, and E If you checked 12d of Part I, complete Sections A and D, and complete Part V) Section A. All Supporting Organizations

Yes No Are all of the organization's supported organizations listed by name in the organization's governing documents? 1 If "No," describe in Part VI how the supported organizations are designated If designated by class or purpose, describe the designation If historic and continuing relationship, explain 1 Did the organization have any supported organization that does not have an IRS determination of status under section 509

(a)(1) or (2)? If "Yes," explain in **Part VI** how the organization determined that the supported organization was described in section 509(a)(1) or (2)2 Did the organization have a supported organization described in section 501(c)(4), (5), or (6)? If "Yes," answer (b) and (c) below

3а Did the organization confirm that each supported organization qualified under section 501(c)(4), (5), or (6) and satisfied the public support tests under section 509(a)(2)? If "Yes," describe in Part VI when and how the organization made the

determination 3b Did the organization ensure that all support to such organizations was used exclusively for section 170(c)(2)(B) purposes? If "Yes," explain in Part VI what controls the organization put in place to ensure such use 3с Was any supported organization not organized in the United States ("foreign supported organization")? If "Yes" and if you

checked 12a or 12b in Part I, answer (b) and (c) below 4a Did the organization have ultimate control and discretion in deciding whether to make grants to the foreign supported organization? If "Yes," describe in Part VI how the organization had such control and discretion despite being controlled or 4b supervised by or in connection with its supported organizations

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)? 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 4c Did the organization add, substitute, or remove any supported organizations during the tax year? If "Yes," answer (b) and (c) below (if applicable) Also, provide detail in Part VI, including (i) the names and EIN numbers of the supported

organizations added, substituted, or removed, (ii) the reasons for each such action, (iii) the authority under the organization's organizing document authorizing such action, and (iv) how the action was accomplished (such as by 5a

amendment to the organizing document) 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? Substitutions only. Was the substitution the result of an event beyond the organization's control?

5b 5c Did the organization provide support (whether in the form of grants or the provision of services or facilities) to anyone other

than (1) its supported organizations. (ii) individuals that are part of the charitable class benefited by one or more of its

6

7

8

answer line 10b below

the organization had excess business holdings)

supported organizations, or (III) other supporting organizations that also support or benefit one or more of the filing organization's supported organizations? If "Yes," provide detail in Part VI. 6

Did the organization provide a grant, loan, compensation, or other similar payment to a substantial contributor (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? If "Yes," complete Part I of Schedule L (Form 990 or 990-EZ)

7 Did the organization make a loan to a disqualified person (as defined in section 4958) not described in line 7? If "Yes,"

complete Part I of Schedule L (Form 990 or 990-EZ)

8 Was the organization controlled directly or indirectly at any time during the tax year by one or more disqualified persons as defined in section 4946 (other than foundation managers and organizations described in section 509(a)(1) or (2))? If "Yes,"

provide detail in Part VI.

9a Did one or more disqualified persons (as defined in line 9a) hold a controlling interest in any entity in which the supporting

organization had an interest? If "Yes," provide detail in Part VI.

Did a disqualified person (as defined in line 9a) have an ownership interest in, or derive any personal benefit from, assets in

9b which the supporting organization also had an interest? If "Yes," provide detail in Part VI.

9с

Did the organization have any excess business holdings in the tax year? (Use Schedule C, Form 4720, to determine whether

Was the organization subject to the excess business holdings rules of section 4943 because of section 4943(f) (regarding

10a certain Type II supporting organizations, and all Type III non-functionally integrated supporting organizations)? If "Yes,"

10a

10b

Schedule A (Form 990 or 990-EZ) 2018

>cn	edule A (Form 990 or 990-E2) 2018		F	age 5
Pa	rt IV Supporting Organizations (continued)			
			Yes	No
11	Has the organization accepted a gift or contribution from any of the following persons?			
а	A person who directly or indirectly controls, either alone or together with persons described in (b) and (c) below, the			
	governing body of a supported organization?	11a		
b	A family member of a person described in (a) above?	11b		
C	A 35% controlled entity of a person described in (a) or (b) above? If "Yes" to a, b, or c, provide detail in Part VI	11 c		
S	ection B. Type I Supporting Organizations			
			Yes	No
1	Did the directors, trustees, or membership of one or more supported organizations have the power to regularly appoint or elect at least a majority of the organization's directors or trustees at all times during the tax year? If "No," describe in Part VI how the supported organization(s) effectively operated, supervised, or controlled the organization's activities. If the organization had more than one supported organization, describe how the powers to appoint and/or remove directors or trustees were allocated among the supported organizations and what conditions or restrictions, if any, applied to such powers during the tax year.	1		
2	Did the organization operate for the benefit of any supported organization other than the supported organization(s) that operated, supervised, or controlled the supporting organization? If "Yes," explain in Part VI how providing such benefit carried out the purposes of the supported organization(s) that operated, supervised or controlled the supporting	2		
	organization	-		
S	ection 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)? If "No," describe in Part VI how control or management of the supporting organization was vested in the same persons that controlled or managed the supported organization(s)	1		
_	<u> </u>			
	ection 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?		103	-140
		1		
2	Were any of the organization's officers, directors, or trustees either (i) appointed or elected by the supported organization (s) or (ii) serving on the governing body of a supported organization? If "No," explain in Part VI how the organization maintained a close and continuous working relationship with the supported organization(s)			
		2		
3	By reason of the relationship described in (2), 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? If "Yes," describe in Part VI the role the organization's supported organizations played in this regard	3		
S	ection E. Type III Functionally-Integrated Supporting Organizations		l	
1	Check the box next to the method that the organization used to satisfy the Integral Part Test during the year (see instruction)	ions)		
	The organization satisfied the Activities Test Complete line 2 below	•		
	b			
	The organization supported a governmental entity Describe in Part VI how you supported a government entity (see	instru	ctions)	
2	Activities Test Answer (a) and (b) below.	į	Yes	No
	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? If "Yes," then in Part VI identify those supported organizations and explain how these activities directly furthered their exempt purposes, how the organization was responsive to those supported organizations, and how the organization determined that these activities constituted substantially all of its activities	2a		
	b Did the activities described in (a) constitute activities that, but for the organization's involvement, one or more of the organization's supported organization(s) would have been engaged in? If "Yes," explain in Part VI the reasons for the organization's position that its supported organization(s) would have engaged in these activities but for the organization's involvement			
,		2b		
3	Parent of Supported Organizations Answer (a) and (b) 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>Provide details in Part VI.</i>	3a		
	b Did the organization exercise a substantial degree of direction over the policies, programs and activities of each of its supported organizations? If "Yes," describe in Part VI. the role played by the organization in this regard	3h		

Sched	lule A (Form 990 or 990-EZ) 2018			Page 6
Pai	t V Type III Non-Functionally Integrated 509(a)(3) Supporting O	rgani	zations	
1	Check here if the organization satisfied the Integral Part Test as a qualifying truinstructions. All other Type III non-functionally integrated supporting organizations.			
	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)	1		
а	Average monthly value of securities	1a		
b	Average monthly cash balances	1 b		
С	Fair market value of other non-exempt-use assets	1c		
d	Total (add lines 1a, 1b, and 1c)	1d		
е	Discount claimed for blockage or other factors (explain in detail in Part VI)			
2	Acquisition indebtedness applicable to non-exempt use assets	2		
3	Subtract line 2 from line 1d	3		
4	Cash deemed held for exempt use Enter 1-1/2% of line 3 (for greater amount, see instructions)	4		
5	Net value of non-exempt-use assets (subtract line 4 from line 3)	5		
6	Multiply line 5 by 035	6		
7	Recoveries of prior-year distributions	7		
8	Minimum Asset Amount (add line 7 to line 6)	8		
	Section C - Distributable Amount		_	Current Year
1	Adjusted net income for prior year (from Section A, line 8, Column A)	1		
2	Enter 85% of line 1	2		
3	Minimum asset amount for prior year (from Section B, line 8, Column A)	3		
4	Enter greater of line 2 or line 3	4		
5	Income tax imposed in prior year	5		
6	Distributable Amount. Subtract line 5 from line 4, unless subject to emergency temporary reduction (see instructions)	6		
7	Check here if the current year is the organization's first as a non-functionally-instructions)	ntegrat	ed Type III supporting or	ganızatıon (see

Schedule A (Form 990 or 990-EZ) (2018)

c Remainder Subtract lines 4a and 4b from 4

5 Remaining underdistributions for years prior to 2018, if any Subtract lines 3g and 4a from line 2
If the amount is greater than zero, explain in Part VI

Remaining underdistributions for 2018 Subtract lines 3h and 4b from line 1. If the amount is greater than zero, explain in Part VI. See instructions.
 Excess distributions carryover to 2019. Add lines.

a Excess from 2014. **b** Excess from 2015. **c** Excess from 2016.

See instructions

d Excess from 2017.e Excess from 2018.

3_j and 4c

8 Breakdown of line 7

Additional Data

Software ID:

Software Version:

EIN: 23-7076021

Name: OSTEOGENESIS IMPERFECTA FOUNDATION INC

Schedule A	(Form 990 or 990-EZ) 2018	Page
Part VI	Supplemental Information. Provide the explanations required by Part II, line 10, Part II, line 17a or 17b, Part III, line 12 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 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, P 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 instructions)	C, line 1, art V

instructions)

Facts And Circumstances Test

SCHEDULE D

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

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 the latest information. OMB No 1545-0047

DLN: 93493100003160

Open to Public Inspection

Department of the Treasury Internal Revenue Service

(Form 990)

1 2

ar	me of the organization		Employer identification number	_
STI	EOGENESIS IMPERFECTA FOUNDATION INC		23-7076021	
'a	rt I Organizations Maintaining Donor Adv		<u> </u>	_
	Complete if the organization answered "Ye	(a) Donor advised funds	(b)Funds and other accounts	
	Total number at end of year	(a) Donor advised funds	(b) unds and other accounts	_
	Aggregate value of contributions to (during year)			_
	Aggregate value of grants from (during year)			-
	Aggregate value at end of year			_
	Did the organization inform all donors and donor advisor	rs in writing that the assets held in don	or advised funds are the	_
	organization's property, subject to the organization's ex	cclusive legal control?	☐ Yes ☐ No	
	Did the organization inform all grantees, donors, and d charitable purposes and not for the benefit of the dono private benefit?			
ar	t II Conservation Easements. Complete if t	ne organization answered "Yes" on		-
	Purpose(s) of conservation easements held by the orga			_
	Preservation of land for public use (e.g., recreation		of an historically important land area	
	Protection of natural habitat	· —	of a certified historic structure	
	Preservation of open space		or a certified motorie structure	
	Complete lines 2a through 2d if the organization held a	avalend concernation contribution in th	so form of a concentration	
	easement on the last day of the tax year	qualified conservation contribution in tr	Held at the End of the Year	1
3	Total number of conservation easements		2a	1
b	Total acreage restricted by conservation easements		2b	1
0	Number of conservation easements on a certified histor	c structure included in (a)	2c	1
t	Number of conservation easements included in (c) acquistructure listed in the National Register	ired after 7/25/06, and not on a historic	2d	
	Number of conservation easements modified, transferred tax year ▶	ed, released, extinguished, or terminate	d by the organization during the	
	Number of states where property subject to conservation	on easement is located >		
			Hing of welstern	
	Does the organization have a written policy regarding t and enforcement of the conservation easements it hold	s?	Yes No	
	Staff and volunteer hours devoted to monitoring, inspe	cting, handling of violations, and enforci	ng conservation easements during the year	
	Amount of expenses incurred in monitoring, inspecting. ▶ \$	handling of violations, and enforcing co	nservation easements during the year	
	Does each conservation easement reported on line 2(d and section 170(h)(4)(B)(\parallel)?	above satisfy the requirements of section	on 170(h)(4)(B)(ı)	
	In Part XIII, describe how the organization reports conbalance sheet, and include, if applicable, the text of the	footnote to the organization's financial	expense statement, and	
11	the organization's accounting for conservation easemer Organizations Maintaining Collections	of Art, Historical Treasures, or	Other Similar Assets.	_
1	Complete if the organization answered "Ye If the organization elected, as permitted under SFAS 1 art, historical treasures, or other similar assets held for	L6 (ASC 958), not to report in its revenu		_
_	provide, in Part XIII, the text of the footnote to its final If the organization elected, as permitted under SFAS 1.	ncial statements that describes these ite	ems	
,	historical treasures, or other similar assets held for put following amounts relating to these items			
(i	i) Revenue included on Form 990, Part VIII, line 1		> \$	
(ii	Assets included in Form 990, Part X		> \$	
	If the organization received or held works of art, histor following amounts required to be reported under SFAS		financial gain, provide the	
3	Revenue included on Form 990, Part VIII, line 1		> \$	
h	Assets included in Form 990 Part X		<u> </u>	

Cat No 52283D

Schedule D (Form 990) 2018

Par	1111	Organizations Ma	aintaining Col	lections (of Art,	Histori	cal Tı	eası	ires, oi	Other	Similar A	Assets	(continued)
3		the organization's acqu (check all that apply)	uisition, accessior	n, and other	r records	, check	any of	the fo	ollowing t	hat are a	significant	t use of it	s collection
а		Public exhibition				d		Loan	or exch	ange prog	grams		
b		Scholarly research				e		Othe	r				
С		Preservation for future	generations										
4	Provid Part X	le a description of the d	organization's coll	lections and	d explain	how the	ey furth	er th	e organız	ation's e	xempt pur	oose in	
5		g the year, did the orga s to be sold to raise fun									nılar	□ Y	es 🗌 No
Pai	t IV	Escrow and Custo Complete if the org X, line 21.			" on Fo	rm 990	, Part	IV, lı	ine 9, oi	r reporte	ed an am	ount on	Form 990, Part
1a		organization an agent, ed on Form 990, Part >		an or other	ınterme	diary for	contril	oution	ns or othe	er assets	not	☐ Y	es 🗆 No
b	If "Ye	s," explain the arrange	ment in Part XIII	and comple	ete the f	ollowing	table					Amount	
С	Begini	ning balance				_				1c			
d	Addıtı	ons during the year								1d			
е		outions during the year	-							1e			
f	Endin	g balance								1f			
2a		e organization include	an amount on Eo	rm 990 Ba	rt V line	21 for	occrou	or c	ıstodial a	ccount li	ability2		es 🗆 No
		s," explain the arrange										_	es 🗆 No
b Da	rt V	Endowment Fund											
	I C V	Endowment Fund	us. Complete ii	(a)Currer			rior yea			ears back	(d)Three y		(e)Four years back
1 a	Beginni	ng of year balance .		(2)000	,	(-)	,		(-)		(4)		(C) our years such
	-	utions						-					
		estment earnings, gain	s. and losses					\dashv					
		or scholarships						_					
		expenditures for facilities						-					
Ū		ograms											
f	Adminis	strative expenses .											
g	End of	year balance											
2	Provid	le the estimated percer	ntage of the curre	ent year end	d balance	e (line 1	g, colu	mn (a)) held a	s			<u> </u>
а		designated or quasi-ei		•				•	••				
ь	Perma	nent endowment 🟲											
c	Temp	orarıly restricted endov	vment ▶										
·		ercentages on lines 2a,		ld equal 10	0%								
3a	Are th	ere endowment funds ization by				ition tha	t are h	eld an	ıd admını	stered fo	r the		Yes No
	(i) un	related organizations										3	Ba(i)
	(ii) re	elated organizations .										3	a(ii)
b		s" on 3a(11), are the rel	-					٠.				. [3b
4		ibe in Part XIII the inte			n's endo	wment	funds						
Pai	rt VI	Land, Buildings, a Complete if the org			" on Fo	rm 000	Dort	T\/	no 115	Coo Fo	rm 000 [onet V lu	no 10
	Descrip	ption of property	(a) Cost or oth (investme	er basıs		t or other					depreciation		(d) Book value
1-	Land				-								
					-							+	
		gs			-							+	
		old improvements						0 522			21.00	7	0 435
		ent						29,522 29,896			21,087		8,435
		nes 1a through 1e (Co	dumn (d) must s	qual Form C	190 Part	· X colu					101,39.	-	28,505
	Auu I	mes ta anough te (Co	namm (u) must et	14411011113	Ju, rait	A, Colul	(<i>D)</i>		-0(0//	•	<u>-</u>	hedule !	36,940 D (Form 990) 2018

Part VII Investments—Other Securities. Complete if the of See Form 990, Part X, line 12.	organization	answe	ered "Yes" on	Form 990, Pa	rt IV, line 11b.
(a) Description of security or category (including name of security)	Во	ok lue		(c) Method of v or end-of-year	
(1) Financial derivatives (2) Closely-held equity interests (3)Other					
(A)					
(B)					
(C)					
(D)					
(E)					
(F)					
(G)					
(H)					
Total. (Column (b) must equal Form 990, Part X, col (B) line 12)	•				
Part VIII Investments—Program Related. Complete if the organization answered 'Yes' on Form	m 990, Part 1	V, line	e 11c. See Fo	rm 990, Part 1	X, line 13.
(a) Description of investment	(b) Book v	alue		(c) Method of v or end-of-year	
(1)					
(2)					
(3)					
(4)					
(5)					
(6)					
(7)					
(8)					
(9)					
Total. (Column (b) must equal Form 990, Part X, col (B) line 13) Part IX Other Assets. Complete if the organization answered 'Ye	b Si on Form 00	O Bast	: T)/ line 11d S	'00 Form 000 D	art V lina 15
(a) Description	23 01110111133	o, rare	.17, 1110 114 2		(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 answ See Form 990, Part X, line 25.	wered 'Yes' o	n Fori	m 990, Part I		
1. (a) Description of liability (1) Federal income taxes			J. Value		
DEFERRED RENT			58		
(2)					
(3)					
(4) (5)					
(5)					
(6)					
(7)					
(8)					
(9)					
Total. (Column (b) must equal Form 990, Part X, col (B) line 25) 2. Liability for uncertain tax positions In Part XIII, provide the text of the	▶ e footnote to t	he ora	58 anızatıon's fina	ncial statements	that reports the
organization's liability for uncertain tax positions under FIN 48 (ASC 740)					

Page 4

2,007,047

251,327

11,254

2.109.750

Schedule D (Form 990) 2018

2,098,496

3 3 1,824,087 4 Amounts included on Form 990, Part VIII, line 12, but not on line 1

Reconciliation of Revenue per Audited Financial Statements With Revenue per Return

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

Total revenue, gains, and other support per audited financial statements

Schedule D (Form 990) 2018

Donated services and use of facilities . . .

Other (Describe in Part XIII)

Supplemental Information

Amounts included on Form 990, Part IX, line 25, but not on line 1: Investment expenses not included on Form 990, Part VIII, line 7b . .

Add lines **4a** and **4b**

Total expenses Add lines 3 and 4c. (This must equal Form 990, Part I, line 18)

XI, lines 2d and 4b, and Part XII, lines 2d and 4b. Also complete this part to provide any additional information

Add lines 2a through 2d

Part XI

1

c

d

3

4

b

5

Part XIII

See Additional Data Table

Return Reference

Investment expenses not included on Form 990, Part VIII, line 7b . 4a 4b 11,254 b Add lines **4a** and **4b** 4c c

11,254 Total revenue Add lines 3 and 4c. (This must equal Form 990, Part I, line 12) 1,835,341 Reconciliation of Expenses per Audited Financial Statements With Expenses per Return.

5 Part XII Complete if the organization answered 'Yes' on Form 990, Part IV, line 12a. 1 2,349,823 2 Amounts included on line 1 but not on Form 990, Part IX, line 25

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

2a

2b

2c

2d

4a

4b

Explanation

47,077

204,250

11.254

2e

3

4c

5

Schedule D (Form 990) 2018	Page 5
Part XIII Supplemental Information (continued) Return Reference Explanation Head of the continued of the c	
Return Reference	Explanation

Schedule D (Form 990) 2018

Additional Data

Software ID: Software Version:

EIN: 23-7076021

Name: OSTEOGENESIS IMPERFECTA FOUNDATION INC

Supplemental Information

Return Reference Explanation

PART X, LINE 2

THE FOUNDATION HAS NO UNCERTAIN TAX POSITIONS THAT QUALIFY FOR EITHER RECOGNITION OR DISCL OSURE IN THE FINANCIAL STATEMENTS, AND NO INTEREST AND PENALITIES HAVE BEEN RECORDED IN THE ACCOMPANYING FINANCIAL STATEMENTS RELATED TO UNCERTAIN TAX POSITIONS

Supplemental Information	
Return Reference	Explanation
PART XI, LINE 2D - OTHER ADJUSTMENTS	SPECIAL EVENT EXPENSES 204,250

.

Supplemental Information	
Return Reference	Explanation
PART XI, LINE 4B - OTHER ADJUSTMENTS	INVESTMENT EXPENSE 11,254

Supplemental Information	
Return Reference	Explanation
PART XII, LINE 2D - OTHER ADJUSTMENTS	SPECIAL EVENT EXPENSES 204,250

Supplemental Information	
Return Reference	Explanation
PART XII, LINE 4B - OTHER ADJUSTMENTS	INVESTMENT EXPENSE 11,254

SCHEDULE G (Form 990 or 990-EZ)

Department of the Treasury

Internal Revenue Service

licensing

Supplemental Information Regarding Fundraising or Gaming Activities

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

> Attach to Form 990 or Form 990-EZ. Go to www irs gov/Form990 for instructions and the latest information

Open to Public Inspection

2018

DLN: 93493100003160 OMB No 1545-0047

lam ST	e of the organization EOGENESIS IMPERFECTA FOUN	DATION INC						entification number			
							23-7076021				
Pa		Fundraising Activities. Complete if the organization answered "Yes" on Form 990, Part IV, line 17. Form 990-EZ filers are not required to complete this part. The whether the organization raised funds through any of the following activities. Check all that apply and solicitations Complete this part									
1	Indicate whether the organiza	tion raised funds th	rough an	y of the fo	ollowing activities Check	all that a	oply				
а	Mail solicitations			е	e Solicitation of non-government grants						
b	☐ Internet and email solicita	tions		f	Solicitation of gov	/ernment g	grants				
Part I Fundraising Activities. Complete if the organization answered "Yes" on Form 990, Part IV, line 17 Form 990-EZ filers are not required to complete this part. 1 Indicate whether the organization raised funds through any of the following activities. Check all that apply a Mail solicitations e Solicitation of non-government grants b Internet and email solicitations f Solicitation of government grants. 2 Did the organization have a written or oral agreement with any individual (including officers, directors, trustees or key employees listed in Form 990, Part VII) or entity in connection with professional fundraising services? Yes If "Yes," list the ten highest paid individuals or entities (fundraisers) pursuant to agreements under which the fundraiser to be compensated at least \$5,000 by the organization 1) Name and address of individual or entitly (iii) Did fundraiser have custody or control of contributions? (iv) Amount paid to (or retained by) fundraiser listed in col (ii)											
d	☐ In-person solicitations										
	or key employees listed in For If "Yes," list the ten highest pa	m 990, Part VII) or aid individuals or er	entity in ntities (fu	connectio	on with professional fund	raising ser	vices? 🔲 Y				
i) l				iser have ody or trol of butions?		(or re fundra	etained by) aiser listed in	(or retained by)			
			Yes	No							
ota	al		1	 							

3 List all states in which the organization is registered or licensed to solicit contributions or has been notified it is exempt from registration or

che	dule G (Form 990 or 990-EZ) 2018					F	Page 3				
.1	Does the organization conduct gaming	activities with nonmember	rs?		☐ Yes	□No					
.2	Is the organization a grantor, beneficia formed to administer charitable gaming		a member of a partnership or other entity		□Yes						
3	Indicate the percentage of gaming activ	vity conducted in									
а	The organization's facility			13a			%				
b	An outside facility			13b			%				
4	Enter the name and address of the pers	son who prepares the orga	inization's gaming/special events books and r	ecords							
	Name ►										
	Address ►										
5a	Does the organization have a contract virevenue?	with a third party from who	om the organization receives gaming		□Yes	□No					
b	If "Yes," enter the amount of gaming re amount of gaming revenue retained by		ganization 🕨 \$ and th	ne							
С	If "Yes," enter name and address of the third party										
	Name ►										
	Address ▶										
6	Gaming manager information										
	Name ▶										
	Gaming manager compensation ► \$										
	Description of services provided ▶										
	☐ Director/officer	☐ Employee	☐ Independent contractor								
7	Mandatory distributions										
а	Is the organization required under state retain the state gaming license?	e law to make charitable d	istributions from the gaming proceeds to		Yes	□No					
b	Enter the amount of distributions requirements in the organization's own exempt activities.		uted to other exempt organizations or spent		53						
Pai	t IV Supplemental Informatio	n. Provide the explana	tions required by Part I, line 2b, column blicable. Also provide any additional info				 S.				
_	Return Reference		Explanation								

Schedule G (Form 990 or 990-EZ) 2018

DLN: 93493100003160 Note: To capture the full content of this document, please select landscape mode (11" x 8.5") when printing. OMB No 1545-0047 Schedule I **Grants and Other Assistance to Organizations**, (Form 990) Governments and Individuals in the United States Complete if the organization answered "Yes," on Form 990, Part IV, line 21 or 22. Open to Public ▶ Attach to Form 990. Department of the Inspection ▶ Go to www.irs.gov/Form990 for the latest information. Treasury Internal Revenue Service Name of the organization Employer identification number OSTEOGENESIS IMPERFECTA FOUNDATION INC 23-7076021 **General Information on Grants and Assistance** Part I Does the organization maintain records to substantiate the amount of the grants or assistance, the grantees' eligibility for the grants or assistance, and 1 Describe in Part IV the organization's procedures for monitoring the use of grant funds in the United States 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 (a) Name and address of (b) EIN (c) IRC section (d) Amount of cash (e) Amount of non-(f) Method of valuation (q) Description of (h) Purpose of grant (if applicable) organization (book, FMV, appraisal, noncash assistance or assistance grant cash or government assistance other) (1) See Additional Data (5)(6)(7)(8)(9)(10)(11)(12)Enter total number of section 501(c)(3) and government organizations listed in the line 1 table For Paperwork Reduction Act Notice, see the Instructions for Form 990. Cat No 50055P Schedule I (Form 990) 2018

Schedule I (Form 990) 2018						Page 2	
		Domestic Individue onal space is needed	als. Complete if the org	ganization answered "Yes	" on Form 990, Part IV, line 22		
(a) Type of grant or	r assistance	(b) Number of recipients	(c) Amount of cash grant	(d) Amount of noncash assistance	(e) Method of valuation (book, FMV, appraisal, other)	(f) Description of noncash assistance	
See Additional Data Table			-				
(1)							
(2)							
(3)							
(4)							
(5)							
(6)							
(7)							
Part IV Suppleme	ental Information	on. Provide the inf	ormation required in	Part I, line 2; Part III	, column (b); and any other ac	dditional information.	
Return Reference	Explanation	on					
PART I, LINE 2		AFTER THE GRANT IS AWARDED, THE GRANTEE HAS TO SEND IN A LISTING OF EXPENDITURES ONCE INCURRED. THIS LIST OF EXPENSES IS REVIEWED AND COMPARED TO OTHER SIMILAR GRANTS AND THEIR EXPENDITURES BEFORE THE MONEY IS ISSUED TO THE GRANTEE.					

Additional Data

HEALTH SYSTEM

CHILDREN 12502 USF PINE DR TAMPA, FL 33612

111 MICHIGAN AVENUE NW WASHINGTON, DC 20010 SHRINERS HOSPITALS FOR

Software ID: **Software Version: EIN:** 23-7076021

36-2193608

Name: OSTEOGENESIS IMPERFECTA FOUNDATION INC

(a) Name and address of	(b) EIN	(c) IRC section	(d) Amount of cash	(e) Amount of non-	(f) Method of valuation	
organization		ıf applıcable	grant	cash	(book, FMV, appraisal,	ĺ
or government				assistance	other)	ĺ

501C3

RESEARCH GRANT

Form 990, Schedule I, Part II, Grants and Other Assistance to Domestic Organizations and Domestic Governments. (g) Description of (h) Purpose of grant non-cash assistance or assistance

25,000

CHILDREN'S NATIONAL 52-1640403 501C3 50,000 RESEARCH GRANT

(a) Name and address of (b) EIN (c) IRC section (d) Amount of cash (e) Amount of non-(f) Method of valuation (a) Description of (h) Purpose of grant organization ıf applıcable grant cash (book, FMV, appraisal, non-cash assistance or assistance or government other) assistance 47-0049123 501C3 59.815 RESEARCH GRANT UNIVERSITY OF NEBRASKA MEDICAL CENTER 985045 THE NEBRASKA RESEARCH GRANT

MEDICAL CENTER OMAHA, NE 68198 501C3 10,000 ALFRED I DUPONT HOSPITAL 59-0634433 FOR CHILDREN OF THE NEMOURS FND

Form 990, Schedule I, Part II, Grants and Other Assistance to Domestic Organizations and Domestic Governments.

1600 ROCKLAND ROAD WILMINGTON, DE 19803

(a) Name and address of **(b)** EIN (c) IRC section (d) Amount of cash (e) Amount of non-(f) Method of valuation (a) Description of (h) Purpose of grant if applicable (book, FMV, appraisal, organization grant cash non-cash assistance or assistance or government other) assistance DUKE UNIVERSITY SCHOOL OF 56-0532129 501C3 50.000 RESEARCH GRANT

MEDICINE BOX 104132 DURHAM, NC 27708					
NICHD 31 CENTER DRIVE BUILDING	52-0858115	501C3	50,000		RESEARCH GRANT

31 ROOM 2A47 BETHESDA, MD 20892

Form 990, Schedule I, Part II, Grants and Other Assistance to Domestic Organizations and Domestic Governments.

(a) Name and address of **(b)** EIN (c) IRC section (d) Amount of cash (e) Amount of non-(f) Method of valuation (a) Description of (h) Purpose of grant if applicable (book, FMV, appraisal, organization grant cash non-cash assistance or assistance or government other) assistance HOSPITAL FOR SPECIAL 13-6714749 501C3 25.000 RESEARCH GRANT CHIDGEDY

535 E 70TH STREET NEW YORK, NY 10021					
HUGO W MOSER RESEARCH INSTITUTE AT KENNEDY KRIEGER INC	52-1524967	501C3	8,500		RESEARCH GRANT

Form 990, Schedule I, Part II, Grants and Other Assistance to Domestic Organizations and Domestic Governments.

707 N BROADWAY BALTIMORE, MD 21205

(a)Type of grant or assistance (b)Number of (e)Method of valuation (book, (f)Description of non-cash assistance (c)Amount of (d)Amount of recipients cash grant non-cash assistance FMV, appraisal, other) ASSISTANCE FOR HEARING AIDS PROVIDED 13,331 TO AN INDIVIDUAL WITH OSTEOGENESIS **IMPERFECTA** 8,651 ASSISTANCE FOR BATHROOM MODIFICATIONS PROVIDED TO AN INDIVIDUAL WITH OSTEOGENESIS **IMPERFECTA** ASSISTANCE FOR WHEELCHAIR LIFT FOR 14,863 VAN/VAN PROVIDED TO AN INDIVIDUAL WITH OSTEOGENESIS IMPERFECTA 765 ASSISTANCE FOR BED PROVIDED TO AN INDIVIDUAL WITH OSTEOGENESIS IMPERFECTA ASSISTANCE FOR OCCUPATIONAL 10,413

Form 990, Schedule I, Part III, Grants and Other Assistance to Domestic Individuals.

THERAPIST AND BED PROVIDED TO AN INDIVIDUAL WITH OSTEOGENESIS

IMPERFECTA

(a)Type of grant or assistance (b)Number of (c)Amount of (d)Amount of (e)Method of valuation (book, (f)Description of non-cash assistance recipients cash grant non-cash assistance FMV, appraisal, other) ASSISTANCE FOR FIREFLY ELECTRIC 2.256 ATTACHABLE HANDCYCLE PROVIDED TO AN INDIVIDUAL WITH OSTEOGENESIS IMPERFECTA ASSISTANCE FOR NEW SEAT FOR WHEEL 3,260 CHAIR PROVIDED TO AN INDIVIDUAL WITH OSTEOGENESIS IMPERFECTA ASSISTANCE FOR OUTDOOR RAMP FOR 21,416 HOME ACCESS/ DRIVEWAY PROVIDED TO AN INDIVIDUAL WITH OSTEOGENESIS IMPERFECTA ASSISTANCE FOR TRAVEL/MOVING 4,617 EXPENSES PROVIDED TO AN INDIVIDUAL

5,918

Form 990, Schedule I, Part III, Grants and Other Assistance to Domestic Individuals.

WITH OSTEOGENESIS IMPERFECTA

ASSISTANCE FOR MISCELLANEOUS NEEDS PROVIDED TO AN INDIVIDUAL WITH OSTEOGENESIS IMPERFECTA

efil	e GRAPHIC pr	int - DO NOT PROCESS As	Filed Data	a -	DLN: 934	19310	00003	160
Sch	edule J	Com	pensati	ion Information	OM	1B No	1545-0	0047
(For	n 990)	For certain Officers, Directors, Trustees, Key Employees, and Highest						
Compensated ▶ Complete if the organization answered			ited Employees vered "Yes" on Form 990. Part IV.	ed Employees 7 1 0				
_			▶ Attach	to Form 990.		Open to Public		
•	tment of the Treasury al Revenue Service	► Go to <u>www.irs.gov/re</u>	<u>огтээо</u> тог	instructions and the latest inforn	nation.		ectio	
	me of the organiza	ation ECTA FOUNDATION INC			Employer identificat	ion nu	ımber	
USI	EUGENESIS IMPERF	ECTA FOUNDATION INC			23-7076021			
Pa	rt I Questi	ons Regarding Compensation	1					
							Yes	No
1a				the following to or for a person listed y relevant information regarding thes				
		or charter travel		Housing allowance or residence for p				
	_	companions	片	Payments for business use of person				
		nification and gross-up payments	H	Health or social club dues or initiation. Personal services (e.g., maid, chauf				
	Discretion	ary spending account		reisonal services (e.g., maid, chaul	reur, cher)			
b		kes in line 1a are checked, did the or Il of the expenses described above?		ollow a written policy regarding paym iplete Part III to explain	ent or reimbursement	1b		
2		tion require substantiation prior to r		or allowing expenses incurred by all r, regarding the items checked in line	1.52	2		
	directors, truste	es, officers, including the CEO/Exect	itive Director	r, regarding the items thetked in line	ıa.			
3		f any, of the following the filing orga EO/Executive Director Check all tha		ed to establish the compensation of th	ie			
	_	•		CEO/Executive Director, but explain i	n Part III			
	Compans:	ation committee	✓	Written employment contract				
		ent compensation consultant	V	Compensation survey or study				
		of other organizations	✓	Approval by the board or compensa	tion committee			
4			Part VII, Se	ction A, line 1a, with respect to the fi	ling organization or a			
	related organiza							
a		ance payment or change-of-control p	•	.6. d		4a		No
b c	•	receive payment from, a suppleme receive payment from, an equity-ba	•	•		4b 4c		No No
·	•			olicable amounts for each item in Part	III			110
), 501(c)(4), and 501(c)(29) org		-				
5		ed on Form 990, Part VII, Section A, ontingent on the revenues of	line 1a, did i	the organization pay or accrue any				
а	The organization					5a		No
b	Any related orga	inization? 5a or 5b, describe in Part III				5b		No
6	-	ed on Form 990, Part VII, Section A,	lung 15 did i					
0	compensation c	ontingent on the net earnings of	ilile Ta, did	the organization pay of accrue any				
a	The organization					6a	-	No
b	Any related orga	nization? 6a or 6b, describe in Part III				6b		No
7	•	•	line 1a did i	the organization provide any nonfixed	İ			
•		escribed in lines 5 and 6? If "Yes," de			•	7		No
8		nts reported on Form 990, Part VII, itial contract exception described in		red pursuant to a contract that was section 53 4958-4(a)(3)? If "Yes," de	escribe	8		No
9	If "Yes" on line 5 53 4958-6(c)?	3, did the organization also follow th	e rebuttable	presumption procedure described in	Regulations section	9		
For I	Danorwork Body	ction Act Notice, see the Instruc	tions for Fo	rm 990 Cat No. 5	0053T Schedule 1	(Forn	1 990)	2018

Part II Officers, Directors, Trustees, Key Employees, and Highest Compensated Employees. Use duplicate copies if additional space is needed. For each individual whose compensation must be reported on Schedule J, report compensation from the organization on row (i) and from related organizations, described in the instructions, on row (ii) Do not list any individuals that are not listed on Form 990, Part VII Note. The sum of columns (B)(I)-(III) for each listed individual must equal the total amount of Form 990, Part VII, Section A, line 1a, applicable column (D) and (E) amounts for that individual (A) Name and Title (B) Breakdown of W-2 and/or 1099-MISC compensation (D) Nontaxable (C) Retirement and (E) Total of columns (F) Compensation in column (B) reported other deferred benefits (B)(i)-(D)(i) Base (ii) Bonus & incentive (iii) Other compensation as deferred on prior compensation compensation reportable Form 990 compensation 1 TRACY SMITH HART 183,382 (i) O 7.537 22,489 213,408 CHIEF EXECUTIVE OFFICER 0 (ii)

Schedule J (Form 990) 2018 Part III Supplemental Information Provide the information, explanation, or descriptions required for Part I, lines 1a, 1b, 3, 4a, 4b, 4c, 5a, 5b, 6a, 6b, 7, and 8, and for Part II Also complete this part for any additional information

Schedule J (Form 990) 2018

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(Form 990 or EZ)		Supplemental Information to Form 990 or 990- Complete to provide information for responses to specific questions o Form 990 or 990-EZ or to provide any additional information.			ons on	2018	
▶ Attach to Form 990 or 990-EZ. Open Department of the Treasury ▶ Go to www.irs.qov/Form990 for the latest information. Inst							
Name l Bกิปทย างกิฐ OSTEOGENESIS IM		JNDATION INC			Employer identi 23-7076021	fication number	
990 Schedul	e O, Suppl	emental Informatio	n				
Return Reference				Explanation			
FORM 990, PART VI, SECTION A, LINE 6	UNDATION HANGE TH	MBERSHIP IN THE OI FOUNDATION IS OPEN TO ALL PEOPLE WHO SUPPORT THE MISSION OF THE OI FO DATION THE BOARD OF DIRECTORS DETERMINE THE LEVEL AND BENEFITS OF MEMBERSHIP, AND MAY C NGE THESE FROM TIME TO TIME ALL MEMBERS ARE ENTITLED TO VOTING PRIVILEGES MEMBERSHIP B DMES EFFECTIVE UPON RECEIPT OF DUES					

Return Explanation

990 Schedule O, Supplemental Information

FORM 990, PART VI, BEFORE BEING FILED WITH THE IRS
SECTION B, LINE 11B

990 Schedule O, Supplemental Information Return Reference Explanation

THE CONFLICT OF INTEREST POLICY COVERS ALL MEMBERS OF THE BOARD. ITS COMMITTEES, FOUNDATIO

PART VI,
SECTION B,
LINE 12C

N STAFF AND THEIR IMMEDIATE FAMILIES AND BUSINESS ASSOCIATES IT IS MONITORED BY ANNUAL WR
ITTEN INFORMATION QUESTIONNAIRE FROM THE BOARD PRESIDENT WHICH IS REVIEWED AND MAINTAINED
BY THE AUDIT COMMITTEE CHAIR THE ENTIRE BOARD REVIEWS EACH TRANSACTION TO COME BEFORE THE
BOARD FOR POTENTIAL OR ACTUAL CONFLICTS OF INTEREST IF POTENTIAL OR ACTUAL CONFLICTS (PA
ST, PRESENT OR FUTURE) ARE IDENTIFIED, THE PERSON DETERMINED TO HAVE A CONFLICT IS RECUSED
FROM DELIBERATIONS AND VOTING THE IDENTIFIED CONFLICTS OF INTEREST AND APPROPRIATE RECUS
ALS ARE DOCUMENTED IN THE MINUTES OF EACH BOARD OR COMMITTEE MEETING

FORM 990.

990 Schedule O, Supplemental Information

Return Reference	Explanation
FORM 990, PART VI, SECTION B, LINE 15A	THE PROCESS FOR DETERMINING COMPENSATION OF THE FOLLOWING PERSONS INCLUDES A REVIEW AND AP PROVAL BY INDEPENDENT MEMBERS OF THE EXECUTIVE COMMITTEE COMPARABILITY DATA USED IN THE R EVIEW PROCESS IS OBTAINED FROM NATIONAL HEALTH COUNCIL SALARY SURVEY THE DELIBERATIONS AN D DECISIONS ARE DOCUMENTED IN THE MINUTES OF THE BOARD OR COMMITTEE MEETING THE COMPENSAT ION DETERMINATION PROCESS APPLIES TO THE FOLLOWING OFFICES/POSITIONS AND THE MOST RECENT Y EAR FOR WHICH THIS PROCESS WAS UNDERTAKEN FOR EACH IS IDENTIFIED OFFICE/TITLE YEAR OF MOS T RECENT REVIEW/APPROVAL CHEIF EXECUTIVE OFFICER 2018

Explanation Return Reference

FORM 990. OI FOUNDATION MAKES ITS GOVERNING DOCUMENTS. CONFLICT OF INTEREST POLICY. AND FINANCIAL ST ATEMENTS AVAILABLE TO THE PUBLIC ON THEIR WEBSITE

PART VI. SECTION C.

990 Schedule O, Supplemental Information

LINE 19

990 Schedule O, Supplemental Information Return Explanation Reference NO CHANGES FROM THE PRIOR YEAR

FORM 990, PART XI, LINE 2C