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Form **990****Return of Organization Exempt From Income Tax**

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

OMB No 1545-0047

2012

Open to Public Inspection

Department of the Treasury
Internal Revenue Service

▶ The organization may have to use a copy of this return to satisfy state reporting requirements.

A For the 2012 calendar year, or tax year beginning JUL 1, 2012 and ending JUN 30, 2013

B Check if applicable: <input type="checkbox"/> Address change <input type="checkbox"/> Name change <input type="checkbox"/> Initial return <input type="checkbox"/> Terminated <input type="checkbox"/> Amended return <input type="checkbox"/> Application pending	C Name of organization		D Employer identification number
	OSTEOGENESIS IMPERFECTA FOUNDATION, INC.		23-7076021
	Doing Business As		
	Number and street (or P O box if mail is not delivered to street address)	Room/suite	E Telephone number
	804 W. DIAMOND AVENUE	210	301-947-0083
	City, town, or post office, state, and ZIP code		G Gross receipts \$
	GAITHERSBURG, MD 20878		1,882,804.
	F Name and address of principal officer. TRACY HART		H(a) Is this a group return for affiliates? <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No
	804 W DIAMOND AVENUE, GAITHERSBURG, MD 2087		H(b) Are all affiliates included? <input type="checkbox"/> Yes <input type="checkbox"/> No
			If "No," attach a list. (see instructions)
I Tax-exempt status: <input checked="" type="checkbox"/> 501(c)(3) <input type="checkbox"/> 501(c)() (insert no) <input type="checkbox"/> 4947(a)(1) or <input type="checkbox"/> 527			H(c) Group exemption number ▶
J Website: WWW.OIF.ORG			
K Form of organization: <input checked="" type="checkbox"/> Corporation <input type="checkbox"/> Trust <input type="checkbox"/> Association <input type="checkbox"/> Other ▶			L Year of formation 1970 M State of legal domicile GA

Part I Summary

Activities & Governance	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			
	2 Check this box <input type="checkbox"/> if the organization discontinued its operations or disposed of more than 25% of its net assets.			
	3 Number of voting members of the governing body (Part VI, line 1a)	3	15	
	4 Number of independent voting members of the governing body (Part VI, line 1b)	4	14	
	5 Total number of individuals employed in calendar year 2012 (Part V, line 2a)	5	12	
	6 Total number of volunteers (estimate if necessary)	6	300	
	7a Total unrelated business revenue from Part VIII, column (C), line 12	7a	0.	
	7b Net unrelated business taxable income from Form 990-T, line 34	7b	0.	
	Revenue	8 Contributions and grants (Part VIII, line 1h)	Prior Year	Current Year
		9 Program service revenue (Part VIII, line 2g)	1,452,624.	1,362,661.
10 Investment income (Part VIII, column (A), lines 3, 4, and 7d)		0.	0.	
11 Other revenue (Part VIII, column (A), lines 5, 6d, 8c, 9c, 10c, and 11e)		98,320.	83,713.	
12 Total revenue - add lines 8 through 11 (must equal Part VIII, column (A), line 12)		7,384.	3,118.	
13 Grants and similar amounts paid (Part IX, column (A), lines 1-3)		1,558,328.	1,449,492.	
14 Benefits paid to or for members (Part IX, column (A), line 4)		311,321.	277,148.	
15 Salaries, other compensation, employee benefits (Part IX, column (A), lines 5-10)		0.	0.	
16a Professional fundraising fees (Part IX, column (A), line 11e)		689,701.	714,814.	
b Total fundraising expenses (Part IX, column (D), line 25) ▶ 228,267.		0.	0.	
17 Other expenses (Part IX, column (A), lines 11a-11d, 11f-24e)		463,866.	660,513.	
18 Total expenses. Add lines 13-17 (must equal Part IX, column (A), line 25)		1,464,888.	1,652,475.	
19 Revenue less expenses. Subtract line 18 from line 12		93,440.	<202,983.>	
Net Assets or Fund Balances		20 Total assets (Part X, line 16)	Beginning of Current Year	End of Year
		21 Total liabilities (Part X, line 26)	2,762,282.	2,561,113.
	22 Net assets or fund balances. Subtract line 21 from line 20	447,975.	258,735.	
		2,314,307.	2,302,378.	

Part II Signature Block

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

Sign Here	Signature of officer	Date			
	TRACY HART, CEO	11/14/13			
Paid Preparer Use Only	Print/Type preparer's name	Preparer's signature	Date	Check if self-employed <input type="checkbox"/>	PTIN
	RICHARD D. CASTRO, CPA	[Signature]	11/5/13		P00367721
	Firm's name ▶ THOMPSON, GREENSPON & CO. P. C. CPA'S	Firm's EIN ▶ 54-1029635			
	Firm's address ▶ 4035 RIDGE TOP RD, SUITE 700 FAIRFAX, VA 22030	Phone no	(703) 385-8888		

May the IRS discuss this return with the preparer shown above? (see instructions)

☒ Yes ☐ No15
9/16

Part III Statement of Program Service Accomplishments

Check if Schedule O contains a response to any question in this Part III

☒ X**1** Briefly describe the organization's mission:

TO IMPROVE THE QUALITY OF LIFE FOR PEOPLE WITH OSTEOGENESIS IMPERFECTA (OI), THROUGH (A) RESEARCH TO FIND A CURE, (B) EDUCATION (C) AWARENESS, AND (D) MUTUAL SUPPORT.

2 Did the organization undertake any significant program services during the year which were not listed on the prior Form 990 or 990-EZ?☐ Yes ☒ No

If "Yes," describe these new services on Schedule O.

3 Did the organization cease conducting, or make significant changes in how it conducts, any program services?☐ Yes ☒ No

If "Yes," describe these changes on Schedule O.

4 Describe the organization's program service accomplishments for each of its three largest program services, as measured by expenses. Section 501(c)(3) and 501(c)(4) organizations are required to report the amount of grants and allocations to others, the total expenses, and revenue, if any, for each program service reported.

4a (Code) (Expenses \$ 459,711. including grants of \$ 219,574.) (Revenue \$)
 THE FOUNDATION FUNDS GRANTS TO SUPPORT RESEARCH RELEVANT TO UNDERSTANDING AND TREATING OSTEOGENESIS IMPERFECTA. FELLOWSHIPS ARE AWARDED TO POST-DOCTORAL TRAINEES WORKING ON PROJECTS WITH CLEAR RELEVANCE TO OI. SEED GRANTS ARE AWARDED FOR BASIC RESEARCH AND CLINICAL STUDIES TO FOSTER PROOF OF CONCEPT STUDIES. THE OI FOUNDATION 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. EVERY THIRD YEAR, THE OIF JOINS OTHER OI ASSOCIATIONS AT THE INTERNATIONAL SCIENTIFIC CONGRESS ON OI. THE NEXT INTERNATIONAL SCIENTIFIC CONGRESS ON OI WILL BE HELD IN WILMINGTON, DE IN 2014.

4b (Code) (Expenses \$ 527,594. including grants of \$ 57,574.) (Revenue \$)
 THE FOUNDATION OFFERS MEDICALLY VERIFIED INFORMATION RELATED TO OSTEOGENESIS IMPERFECTA. TOPICS INCLUDE MEDICAL ISSUES SUCH AS GENETICS, DIAGNOSIS AND TREATMENTS. ADDITIONAL TOPICS FOCUS ON DAILY LIVING STRATEGIES, SCHOOL AND EMPLOYMENT. FOUNDATION STAFF REPLIES TO REQUESTS FOR INFORMATION VIA 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, THE FACT SHEETS, BOOKLETS AND BROCHURES. INFORMATION ON OSTEOGENESIS IMPERFECTA IS WRITTEN FOR A VARIETY OF AUDIENCES INCLUDING MEDICAL PROFESSIONALS, PARENTS AND OTHER FAMILY MEMBERS, CHILDREN, ADULTS WHO HAVE OI AND

4c (Code) (Expenses \$ 61,896. including grants of \$) (Revenue \$ 3,118.)
 THE OSTEOGENESIS IMPERFECTA FOUNDATION (OIF) STRIVES TO BUILD PUBLIC AWARENESS AND GENERATE ADDITIONAL SUPPORT AMONG PEOPLE WITH OSTEOGENESIS IMPERFECTA (OI), COMMUNITY ORGANIZATIONS, GOVERNMENT AGENCIES, THE GENERAL PUBLIC, SCHOOL PERSONNEL AND MEDICAL PROFESSIONALS. THE FOUNDATION HAS A PUBLIC SERVICE ANNOUNCEMENT, PARTNERS WITH RELATED 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, THE FEDERAL WORKING GROUP ON BONE, AND THE OI FEDERATION OF EUROPE. IN ADDITION, THE OIF PARTICIPATES IN RARE DISEASE DAY ACTIVITIES, AND EACH MAY SPONSORS OI AWARENESS WEEK. IN 2013 AWARENESS WEEK VOLUNTEERS IN 25 STATES HELD FUNDRAISING EVENTS, SECURED

4d Other program services (Describe in Schedule O.)

(Expenses \$ 262,884. including grants of \$) (Revenue \$)

4e Total program service expenses 1,312,085.

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Part IV Checklist of Required Schedules

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

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Part IV Checklist of Required Schedules (continued)

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

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

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Part V Statements Regarding Other IRS Filings and Tax ComplianceCheck if Schedule O contains a response to any question in this Part V ☐

		Yes	No
1a	Enter the number reported in Box 3 of Form 1096. Enter -0- if not applicable		
1b	Enter the number of Forms W-2G included in line 1a. Enter -0- if not applicable		
c	Did the organization comply with backup withholding rules for reportable payments to vendors and reportable gaming (gambling) winnings to prize winners?	X	
2a	Enter the number of employees reported on Form W-3, Transmittal of Wage and Tax Statements, filed for the calendar year ending with or within the year covered by this return		
b	If at least one is reported on line 2a, did the organization file all required federal employment tax returns? Note. If the sum of lines 1a and 2a is greater than 250, you may be required to e-file (see instructions)	X	
3a	Did the organization have unrelated business gross income of \$1,000 or more during the year?		X
3b	If "Yes," has it filed a Form 990-T for this year? If "No," provide an explanation in Schedule O		
4a	At any time during the calendar year, did the organization have an interest in, or a signature or other authority over, a financial account in a foreign country (such as a bank account, securities account, or other financial account)?		X
b	If "Yes," enter the name of the foreign country: See instructions for filing requirements for Form TD F 90-22.1, Report of Foreign Bank and Financial Accounts.		
5a	Was the organization a party to a prohibited tax shelter transaction at any time during the tax year?		X
5b	Did any taxable party notify the organization that it was or is a party to a prohibited tax shelter transaction?		X
5c	If "Yes," to line 5a or 5b, did the organization file Form 8886-T?		
6a	Does the organization have annual gross receipts that are normally greater than \$100,000, and did the organization solicit any contributions that were not tax deductible as charitable contributions?		X
6b	If "Yes," did the organization include with every solicitation an express statement that such contributions or gifts were not tax deductible?		
7	Organizations that may receive deductible contributions under section 170(c).		
a	Did the organization receive a payment in excess of \$75 made partly as a contribution and partly for goods and services provided to the payor?		X
b	If "Yes," did the organization notify the donor of the value of the goods or services provided?		
c	Did the organization sell, exchange, or otherwise dispose of tangible personal property for which it was required to file Form 8282?		X
d	If "Yes," indicate the number of Forms 8282 filed during the year		
e	Did the organization receive any funds, directly or indirectly, to pay premiums on a personal benefit contract?		X
f	Did the organization, during the year, pay premiums, directly or indirectly, on a personal benefit contract?		X
g	If the organization received a contribution of qualified intellectual property, did the organization file Form 8899 as required?		
h	If the organization received a contribution of cars, boats, airplanes, or other vehicles, did the organization file a Form 1098-C?		
8	Sponsoring organizations maintaining donor advised funds and section 509(a)(3) supporting organizations. Did the supporting organization, or a donor advised fund maintained by a sponsoring organization, have excess business holdings at any time during the year?		
9	Sponsoring organizations maintaining donor advised funds.		
a	Did the organization make any taxable distributions under section 4966?		
b	Did the organization make a distribution to a donor, donor advisor, or related person?		
10	Section 501(c)(7) organizations. Enter:		
a	Initiation fees and capital contributions included on Part VIII, line 12		
b	Gross receipts, included on Form 990, Part VIII, line 12, for public use of club facilities		
11	Section 501(c)(12) organizations. Enter:		
a	Gross income from members or shareholders		
b	Gross income from other sources (Do not net amounts due or paid to other sources against amounts due or received from them)		
12a	Section 4947(a)(1) non-exempt charitable trusts. Is the organization filing Form 990 in lieu of Form 1041?		
b	If "Yes," enter the amount of tax-exempt interest received or accrued during the year		
13	Section 501(c)(29) qualified nonprofit health insurance issuers.		
a	Is the organization licensed to issue qualified health plans in more than one state? Note. See the instructions for additional information the organization must report on Schedule O.		
b	Enter the amount of reserves the organization is required to maintain by the states in which the organization is licensed to issue qualified health plans		
c	Enter the amount of reserves on hand		
14a	Did the organization receive any payments for indoor tanning services during the tax year?		X
b	If "Yes," has it filed a Form 720 to report these payments? If "No," provide an explanation in Schedule O		

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Part VI Governance, Management, and Disclosure For each "Yes" response to lines 2 through 7b below, and for a "No" response to line 8a, 8b, or 10b below, describe the circumstances, processes, or changes in Schedule O. See instructions.

Check if Schedule O contains a response to any question in this Part VI

☒ X**Section A. Governing Body and Management**

	Yes	No
1a Enter the number of voting members of the governing body at the end of the tax year If there are material differences in voting rights among members of the governing body, or if the governing body delegated broad authority to an executive committee or similar committee, explain in Schedule O	15	
1b Enter the number of voting members included in line 1a, above, who are independent	14	
2 Did any officer, director, trustee, or key employee have a family relationship or a business relationship with any other officer, director, trustee, or key employee?		X
3 Did the organization delegate control over management duties customarily performed by or under the direct supervision of officers, directors, or trustees, or key employees to a management company or other person?		X
4 Did the organization make any significant changes to its governing documents since the prior Form 990 was filed?		X
5 Did the organization become aware during the year of a significant diversion of the organization's assets?		X
6 Did the organization have members or stockholders?	X	
7a Did the organization have members, stockholders, or other persons who had the power to elect or appoint one or more members of the governing body?		X
7b Are any governance decisions of the organization reserved to (or subject to approval by) members, stockholders, or persons other than the governing body?		X
8 Did the organization contemporaneously document the meetings held or written actions undertaken during the year by the following:		
a The governing body?	X	
b Each committee with authority to act on behalf of the governing body?	X	
9 Is there any officer, director, trustee, or key employee listed in Part VII, Section A, who cannot be reached at the organization's mailing address? If "Yes," provide the names and addresses in Schedule O		X

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

	Yes	No
10a Did the organization have local chapters, branches, or affiliates?		X
b If "Yes," did the organization have written policies and procedures governing the activities of such chapters, affiliates, and branches to ensure their operations are consistent with the organization's exempt purposes?		
11a Has the organization provided a complete copy of this Form 990 to all members of its governing body before filing the form?		X
b Describe in Schedule O the process, if any, used by the organization to review this Form 990.		
12a Did the organization have a written conflict of interest policy? If "No," go to line 13	X	
b Were officers, directors, or trustees, and key employees required to disclose annually interests that could give rise to conflicts?	X	
c Did the organization regularly and consistently monitor and enforce compliance with the policy? If "Yes," describe in Schedule O how this was done	X	
13 Did the organization have a written whistleblower policy?	X	
14 Did the organization have a written document retention and destruction policy?	X	
15 Did the process for determining compensation of the following persons include a review and approval by independent persons, comparability data, and contemporaneous substantiation of the deliberation and decision?		
a The organization's CEO, Executive Director, or top management official	X	
b Other officers or key employees of the organization		X
If "Yes" to line 15a or 15b, describe the process in Schedule O (see instructions).		
16a Did the organization invest in, contribute assets to, or participate in a joint venture or similar arrangement with a taxable entity during the year?		X
b If "Yes," did the organization follow a written policy or procedure requiring the organization to evaluate its participation in joint venture arrangements under applicable federal tax law, and take steps to safeguard the organization's exempt status with respect to such arrangements?		

Section C. Disclosure

17 List the states with which a copy of this Form 990 is required to be filed: **AK, AZ, AR, CA, CO, CT, DC, FL, GA, IL, KS, KY**

18 Section 6104 requires an organization to make its Forms 1023 (or 1024 if applicable), 990, and 990-T (Section 501(c)(3)s only) available for public inspection. Indicate how you made these available. Check all that apply.
☒ Own website ☐ Another's website ☒ Upon request ☐ Other (explain in Schedule O)

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

20 State the name, physical address, and telephone number of the person who possesses the books and records of the organization: **THE FOUNDATION - 301-947-0083**
804 W. DIAMOND AVE, SUITE 210, GAITHERSBURG, MD 20878

Part VII Compensation of Officers, Directors, Trustees, Key Employees, Highest Compensated Employees, and Independent ContractorsCheck if Schedule O contains a response to any question in this Part VII ☐**Section A. Officers, Directors, Trustees, Key Employees, and Highest Compensated Employees****1a** Complete this table for all persons required to be listed. Report compensation for the calendar year ending with or within the organization's tax year.

- List all of the organization's **current** officers, directors, trustees (whether individuals or organizations), regardless of amount of compensation. Enter -0- in columns (D), (E), and (F) if no compensation was paid.

- List all of the organization's **current** key employees, if any. See instructions for definition of "key employee."

- List the organization's five **current** highest compensated employees (other than an officer, director, trustee, or key employee) who received reportable compensation (Box 5 of Form W-2 and/or Box 7 of Form 1099-MISC) of more than \$100,000 from the organization and any related organizations.

- List all of the organization's **former** officers, key employees, and highest compensated employees who received more than \$100,000 of reportable compensation from the organization and any related organizations.

- List all of the organization's **former directors or trustees** that received, in the capacity as a former director or trustee of the organization, more than \$10,000 of reportable compensation from the organization and any related organizations.

List persons in the following order: individual trustees or directors; institutional trustees; officers; key employees; highest compensated employees; and former such persons.

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

(A) Name and Title	(B) Average hours per week (list any hours for related organizations below line)	(C) Position (do not check more than one box, unless person is both an officer and a director/trustee)						(D) Reportable compensation from the organization (W-2/1099-MISC)	(E) Reportable compensation from related organizations (W-2/1099-MISC)	(F) Estimated amount of other compensation from the organization and related organizations
		Individual trustee or director	Institutional trustee	Officer	Key employee	Highest compensated employee	Former			
(1) MICHELLE DUPREY, ESQ. SECRETARY	2.00	X		X				0.	0.	0.
(2) MARK BIRDWHISTELL FIRST VICE PRESIDENT	2.00	X		X				0.	0.	0.
(3) SHARON TRAHAN PRESIDENT	2.00	X		X				0.	0.	0.
(4) ANTHONY BENISH TREASURER	2.00	X		X				0.	0.	0.
(5) FRANCIS GLORIEUX, OC, MD, PHD MAC CHAIR	2.00	X						0.	0.	0.
(6) ANNA CURRY GUALANO DIRECTOR	2.00	X						0.	0.	0.
(7) AMANDA BERGMAN DIRECTOR	2.00	X						0.	0.	0.
(8) GIL R. CABACUNGAN, III SECOND VICE PRESIDENT	2.00	X		X				0.	0.	0.
(9) IAN SACKS DIRECTOR	2.00	X						0.	0.	0.
(10) KRISTEN D. ANTOLINI, ESQ. DIRECTOR	2.00	X						0.	0.	0.
(11) JODY W. CHEEK, M.ED. DIRECTOR	2.00	X						0.	0.	0.
(12) ALCIDES ORTIZ, ESQ. DIRECTOR	2.00	X						0.	0.	0.
(13) CAROLYN REDFORD TIPTON DIRECTOR	2.00	X						0.	0.	0.
(14) ROBIN WRIGHT, G.G. DIRECTOR	2.00	X						0.	0.	0.
(15) KENNETH W. GUDEK, SR. DIRECTOR	2.00	X						0.	0.	0.
(16) TRACY SMITH HART CHIEF EXECUTIVE OFFICER	40.00			X				140,200.	0.	14,262.

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

(A) Name and title	(B) Average hours per week (list any hours for related organizations below line)	(C) Position <small>(do not check more than one box, unless person is both an officer and a director/trustee)</small>						(D) Reportable compensation from the organization (W-2/1099-MISC)	(E) Reportable compensation from related organizations (W-2/1099-MISC)	(F) Estimated amount of other compensation from the organization and related organizations
		Individual trustee or director	Institutional trustee	Officer	Key employee	Highest compensated employee	Former			
1b Sub-total							140,200.	0.	14,262.	
c Total from continuation sheets to Part VII, Section A							0.	0.	0.	
d Total (add lines 1b and 1c)							140,200.	0.	14,262.	

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. ▶

:

		Yes	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		X
4	For any individual listed on line 1a, is the sum of reportable compensation and other compensation from the organization and related organizations greater than \$150,000? If "Yes," complete Schedule J for such individual	X	
5	Did any person listed on line 1a receive or accrue compensation from any unrelated organization or individual for services rendered to the organization? If "Yes," complete Schedule J for such person		X

Section B. Independent Contractors

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

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

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

Part VIII Statement of RevenueCheck if Schedule O contains a response to any question in this Part VIII ☐

				(A) Total revenue	(B) Related or exempt function revenue	(C) Unrelated business revenue	(D) Revenue excluded from tax under sections 512, 513, or 514
Contributions, Gifts, Grants and Other Similar Amounts	1 a	Federated campaigns	1a	37,659.			
	b	Membership dues	1b	25,284.			
	c	Fundraising events	1c	423,395.			
	d	Related organizations	1d				
	e	Government grants (contributions)	1e				
	f	All other contributions, gifts, grants, and similar amounts not included above	1f	876,323.			
	g	Noncash contributions included in lines 1a-1f \$					
	h	Total. Add lines 1a-1f		1,362,661.			
Program Service Revenue	2 a		Business Code				
	b						
	c						
	d						
	e						
	f		All other program service revenue				
	g		Total. Add lines 2a-2f				
	Other Revenue	3	Investment income (including dividends, interest, and other similar amounts)		42,547.		
4		Income from investment of tax-exempt bond proceeds					
5		Royalties					
6 a		Gross rents	(i) Real (ii) Personal				
b		Less: rental expenses					
c		Rental income or (loss)					
d		Net rental income or (loss)					
7 a		Gross amount from sales of assets other than inventory	(i) Securities (ii) Other	375,401.			
b		Less: cost or other basis and sales expenses		334,235.			
c		Gain or (loss)		41,166.			
d		Net gain or (loss)		41,166.			41,166.
8 a		Gross income from fundraising events (not including \$ 423,395. of contributions reported on line 1c). See Part IV, line 18	a	94,422.			
b		Less: direct expenses	b	94,422.			
c		Net income or (loss) from fundraising events		0.			
9 a		Gross income from gaming activities. See Part IV, line 19	a				
b		Less: direct expenses	b				
c		Net income or (loss) from gaming activities					
10 a		Gross sales of inventory, less returns and allowances	a	7,773.			
b	Less: cost of goods sold	b	4,655.				
c	Net income or (loss) from sales of inventory		3,118.	3,118.			
Miscellaneous Revenue		Business Code					
11 a							
b							
c							
d	All other revenue						
e	Total. Add lines 11a-11d						
12	Total revenue. See instructions		1,449,492.	3,118.	0.	83,713.	

Part IX Statement of Functional Expenses

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

Check if Schedule O contains a response to any question in this Part IX ☐

	(A) Total expenses	(B) Program service expenses	(C) Management and general expenses	(D) Fundraising expenses
Do not include amounts reported on lines 6b, 7b, 8b, 9b, and 10b of Part VIII.				
1 Grants and other assistance to governments and organizations in the United States. See Part IV, line 21	109,200.	109,200.		
2 Grants and other assistance to individuals in the United States. See Part IV, line 22	119,548.	119,548.		
3 Grants and other assistance to governments, organizations, and individuals outside the United States. See Part IV, lines 15 and 16	48,400.	48,400.		
4 Benefits paid to or for members				
5 Compensation of current officers, directors, trustees, and key employees	173,998.	127,112.	31,573.	15,313.
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	460,614.	205,314.	174,707.	80,593.
8 Pension plan accruals and contributions (include section 401(k) and 403(b) employer contributions)	9,458.	3,217.	5,240.	1,001.
9 Other employee benefits	33,105.	17,392.	4,180.	11,533.
10 Payroll taxes	37,639.	17,392.	14,646.	5,601.
11 Fees for services (non-employees):				
a Management				
b Legal				
c Accounting	12,738.		12,738.	
d Lobbying				
e Professional fundraising services. See Part IV, line 17				
f Investment management fees	32,527.	3.	32,524.	
g Other. (If line 11g amount exceeds 10% of line 25, column (A) amount, list line 11g expenses on Sch O)	48,535.	5,684.	4,289.	38,562.
12 Advertising and promotion				
13 Office expenses	53,607.	16,914.	26,520.	10,173.
14 Information technology	63,897.	42,790.	19,097.	2,010.
15 Royalties				
16 Occupancy	70,076.		70,076.	
17 Travel	19,651.	7,792.	3,949.	7,910.
18 Payments of travel or entertainment expenses for any federal, state, or local public officials				
19 Conferences, conventions, and meetings	259,983.	257,508.	2,048.	427.
20 Interest	4,175.		3,925.	250.
21 Payments to affiliates				
22 Depreciation, depletion, and amortization	17,846.		17,846.	
23 Insurance	7,211.	591.	5,057.	1,563.
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 MEDICAL RESEARCH AND RE	41,670.	41,670.		
b ADVOCACY AND AWARDS	20,304.	20,304.		
c INDIRECT COST ALLOCATIO	0.	267,386.	<316,591.>	49,205.
d				
e All other expenses	8,293.	3,868.	299.	4,126.
25 Total functional expenses. Add lines 1 through 24e	1,652,475.	1,312,085.	112,123.	228,267.
26 Joint costs. Complete this line only if the organization reported in column (B) joint costs from a combined educational campaign and fundraising solicitation				
Check here <input checked="" type="checkbox"/> if following SOP 98-2 (ASC 958-720)	47,234.	44,520.	0.	2,714.

Part X Balance SheetCheck if Schedule O contains a response to any question in this Part X ☐

		(A) Beginning of year		(B) End of year
Assets	1 Cash - non-interest-bearing	172,298.	1	135,868.
	2 Savings and temporary cash investments	253,174.	2	209,649.
	3 Pledges and grants receivable, net	528,278.	3	274,921.
	4 Accounts receivable, net	41,083.	4	78,382.
	5 Loans and other receivables from current and former officers, directors, trustees, key employees, and highest compensated employees. Complete Part II of Schedule L		5	
	6 Loans and other receivables from other disqualified persons (as defined under section 4958(f)(1)), persons described in section 4958(c)(3)(B), and contributing employers and sponsoring organizations of section 501(c)(9) voluntary employees' beneficiary organizations (see instr). Complete Part II of Sch L		6	
	7 Notes and loans receivable, net		7	
	8 Inventories for sale or use	22,048.	8	25,903.
	9 Prepaid expenses and deferred charges	42,070.	9	12,911.
	10a Land, buildings, and equipment: cost or other basis. Complete Part VI of Schedule D	10a 142,749.		
	b Less: accumulated depreciation	10b 117,677.	10c 34,716.	25,072.
	11 Investments - publicly traded securities	1,646,353.	11	1,776,145.
	12 Investments - other securities. See Part IV, line 11		12	
	13 Investments - program-related. See Part IV, line 11		13	
	14 Intangible assets		14	
	15 Other assets. See Part IV, line 11	22,262.	15	22,262.
16 Total assets. Add lines 1 through 15 (must equal line 34)	2,762,282.	16	2,561,113.	
Liabilities	17 Accounts payable and accrued expenses	174,869.	17	183,042.
	18 Grants payable	198,329.	18	70,130.
	19 Deferred revenue	66,912.	19	0.
	20 Tax-exempt bond liabilities		20	
	21 Escrow or custodial account liability. Complete Part IV of Schedule D		21	
	22 Loans and other payables to current and former officers, directors, trustees, key employees, highest compensated employees, and disqualified persons. Complete Part II of Schedule L		22	
	23 Secured mortgages and notes payable to unrelated third parties		23	
	24 Unsecured notes and loans payable to unrelated third parties		24	
	25 Other liabilities (including federal income tax, payables to related third parties, and other liabilities not included on lines 17-24). Complete Part X of Schedule D	7,865.	25	5,563.
	26 Total liabilities. Add lines 17 through 25	447,975.	26	258,735.
	Net Assets or Fund Balances	Organizations that follow SFAS 117 (ASC 958), check here <input checked="" type="checkbox"/> and complete lines 27 through 29, and lines 33 and 34.		
27 Unrestricted net assets		1,554,552.	27	1,890,280.
28 Temporarily restricted net assets		705,267.	28	357,610.
29 Permanently restricted net assets		54,488.	29	54,488.
Organizations that do not follow SFAS 117 (ASC 958), check here <input type="checkbox"/> and complete lines 30 through 34.				
30 Capital stock or trust principal, or current funds			30	
31 Paid-in or capital surplus, or land, building, or equipment fund			31	
32 Retained earnings, endowment, accumulated income, or other funds			32	
33 Total net assets or fund balances		2,314,307.	33	2,302,378.
34 Total liabilities and net assets/fund balances	2,762,282.	34	2,561,113.	

Form 990 (2012)

Part XI Reconciliation of Net AssetsCheck if Schedule O contains a response to any question in this Part XI ☐

1	Total revenue (must equal Part VIII, column (A), line 12)	1	1,449,492.
2	Total expenses (must equal Part IX, column (A), line 25)	2	1,652,475.
3	Revenue less expenses. Subtract line 2 from line 1	3	<202,983.>
4	Net assets or fund balances at beginning of year (must equal Part X, line 33, column (A))	4	2,314,307.
5	Net unrealized gains (losses) on investments	5	191,054.
6	Donated services and use of facilities	6	
7	Investment expenses	7	
8	Prior period adjustments	8	
9	Other changes in net assets or fund balances (explain in Schedule O)	9	0.
10	Net assets or fund balances at end of year. Combine lines 3 through 9 (must equal Part X, line 33, column (B))	10	2,302,378.

Part XII Financial Statements and ReportingCheck if Schedule O contains a response to any question in this Part XII ☒

- 1 Accounting method used to prepare the Form 990: ☐ Cash ☒ Accrual ☐ Other _____
If the organization changed its method of accounting from a prior year or checked "Other," explain in Schedule O.
- 2a Were the organization's financial statements compiled or reviewed by an independent accountant?
If "Yes," check a box below to indicate whether the financial statements for the year were compiled or reviewed on a separate basis, consolidated basis, or both:
☐ Separate basis ☐ Consolidated basis ☐ Both consolidated and separate basis
- b Were the organization's financial statements audited by an independent accountant?
If "Yes," check a box below to indicate whether the financial statements for the year were audited on a separate basis, consolidated basis, or both:
☒ Separate basis ☐ Consolidated basis ☐ Both consolidated and separate basis
- c If "Yes" to line 2a or 2b, does the organization have a committee that assumes responsibility for oversight of the audit, review, or compilation of its financial statements and selection of an independent accountant?
If the organization changed either its oversight process or selection process during the tax year, explain in Schedule O.
- 3a As a result of a federal award, was the organization required to undergo an audit or audits as set forth in the Single Audit Act and OMB Circular A-133?
- 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

	Yes	No
2a		X
2b	X	
2c	X	
3a		X
3b		

Form 990 (2012)

SCHEDULE A
(Form 990 or 990-EZ)

Department of the Treasury
Internal Revenue Service

Public Charity Status and Public Support

Complete if the organization is a section 501(c)(3) organization or a section 4947(a)(1) nonexempt charitable trust.

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

OMB No 1545-0047

2012

Open to Public
Inspection

Name of the organization

OSTEOGENESIS IMPERFECTA FOUNDATION, INC.

Employer identification number

23-7076021

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

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

- 1 ☐ A church, convention of churches, or association of churches described in **section 170(b)(1)(A)(i).**
- 2 ☐ A school described in **section 170(b)(1)(A)(ii).** (Attach Schedule E.)
- 3 ☐ A hospital or a cooperative hospital service organization described in **section 170(b)(1)(A)(iii).**
- 4 ☐ A medical research organization operated in conjunction with a hospital described in **section 170(b)(1)(A)(iii).** Enter the hospital's name, city, and state: _____
- 5 ☐ An organization operated for the benefit of a college or university owned or operated by a governmental unit described in **section 170(b)(1)(A)(iv).** (Complete Part II.)
- 6 ☐ A federal, state, or local government or governmental unit described in **section 170(b)(1)(A)(v).**
- 7 ☐ An organization that normally receives a substantial part of its support from a governmental unit or from the general public described in **section 170(b)(1)(A)(vi).** (Complete Part II.)
- 8 ☐ A community trust described in **section 170(b)(1)(A)(vii).** (Complete Part II.)
- 9 ☒ An organization that normally receives: (1) more than 33 1/3% of its support from contributions, membership fees, and gross receipts from activities related to its exempt functions - subject to certain exceptions, and (2) no more than 33 1/3% of its support from gross investment income and unrelated business taxable income (less section 511 tax) from businesses acquired by the organization after June 30, 1975. See **section 509(a)(2).** (Complete Part III.)
- 10 ☐ An organization organized and operated exclusively to test for public safety. See **section 509(a)(4).**
- 11 ☐ An organization organized and operated exclusively for the benefit of, to perform the functions of, or to carry out the purposes of one or more publicly supported organizations described in section 509(a)(1) or section 509(a)(2). See **section 509(a)(3).** Check the box that describes the type of supporting organization and complete lines 11e through 11h.
- a ☐ Type I b ☐ Type II c ☐ Type III - Functionally integrated d ☐ Type III - Non-functionally integrated
- e ☐ By checking this box, I certify that the organization is not controlled directly or indirectly by one or more disqualified persons other than foundation managers and other than one or more publicly supported organizations described in section 509(a)(1) or section 509(a)(2).
- f ☐ If the organization received a written determination from the IRS that it is a Type I, Type II, or Type III supporting organization, check this box
- g ☐ Since August 17, 2006, has the organization accepted any gift or contribution from any of the following persons?
- (i) A person who directly or indirectly controls, either alone or together with persons described in (ii) and (iii) below, the governing body of the supported organization?
- (ii) A family member of a person described in (i) above?
- (iii) A 35% controlled entity of a person described in (i) or (ii) above?
- h ☐ Provide the following information about the supported organization(s).

	Yes	No
11g(i)		
11g(ii)		
11g(iii)		

(i) Name of supported organization	(ii) EIN	(iii) Type of organization (described on lines 1-9 above or IRC section (see instructions))	(iv) Is the organization in col (i) listed in your governing document?		(v) Did you notify the organization in col (i) of your support?		(vi) Is the organization in col (i) organized in the U S ?		(vii) Amount of monetary support
			Yes	No	Yes	No	Yes	No	
Total									

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

Schedule A (Form 990 or 990-EZ) 2012

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

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

Section A. Public Support

Calendar year (or fiscal year beginning in) ►	(a) 2008	(b) 2009	(c) 2010	(d) 2011	(e) 2012	(f) Total
1 Gifts, grants, contributions, and membership fees received. (Do not include any "unusual grants.")						
2 Tax revenues levied for the organization's benefit and either paid to or expended on its behalf						
3 The value of services or facilities furnished by a governmental unit to the organization without charge						
4 Total. Add lines 1 through 3						
5 The portion of total contributions by each person (other than a governmental unit or publicly supported organization) included on line 1 that exceeds 2% of the amount shown on line 11, column (f)						
6 Public support. Subtract line 5 from line 4						

Section B. Total Support

Calendar year (or fiscal year beginning in) ►	(a) 2008	(b) 2009	(c) 2010	(d) 2011	(e) 2012	(f) Total
7 Amounts from line 4						
8 Gross income from interest, dividends, payments received on securities loans, rents, royalties and income from similar sources						
9 Net income from unrelated business activities, whether or not the business is regularly carried on						
10 Other income. Do not include gain or loss from the sale of capital assets (Explain in Part IV.)						
11 Total support. Add lines 7 through 10						
12 Gross receipts from related activities, etc. (see instructions)					12	
13 First five years. If the Form 990 is for the organization's first, second, third, fourth, or fifth tax year as a section 501(c)(3) organization, check this box and stop here ► <input type="checkbox"/>						

Section C. Computation of Public Support Percentage

14 Public support percentage for 2012 (line 6, column (f) divided by line 11, column (f))	14		%
15 Public support percentage from 2011 Schedule A, Part II, line 14	15		%
16a 33 1/3% support test - 2012. If the organization did not check the box on line 13, and line 14 is 33 1/3% or more, check this box and stop here. The organization qualifies as a publicly supported organization ► <input type="checkbox"/>			
b 33 1/3% support test - 2011. If the organization did not check a box on line 13 or 16a, and line 15 is 33 1/3% or more, check this box and stop here. The organization qualifies as a publicly supported organization ► <input type="checkbox"/>			
17a 10% -facts-and-circumstances test - 2012. If the organization did not check a box on line 13, 16a, or 16b, and line 14 is 10% or more, and if the organization meets the "facts-and-circumstances" test, check this box and stop here. Explain in Part IV how the organization meets the "facts-and-circumstances" test. The organization qualifies as a publicly supported organization ► <input type="checkbox"/>			
b 10% -facts-and-circumstances test - 2011. If the organization did not check a box on line 13, 16a, 16b, or 17a, and line 15 is 10% or more, and if the organization meets the "facts-and-circumstances" test, check this box and stop here. Explain in Part IV how the organization meets the "facts-and-circumstances" test. The organization qualifies as a publicly supported organization ► <input type="checkbox"/>			
18 Private foundation. If the organization did not check a box on line 13, 16a, 16b, 17a, or 17b, check this box and see instructions ► <input type="checkbox"/>			

Schedule A (Form 990 or 990-EZ) 2012

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

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

Section A. Public Support

Calendar year (or fiscal year beginning in) ▶	(a) 2008	(b) 2009	(c) 2010	(d) 2011	(e) 2012	(f) Total
1 Gifts, grants, contributions, and membership fees received. (Do not include any "unusual grants.")	2,021,827.	1,836,616.	1,485,571.	1,482,624.	1,402,661.	8,229,299.
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	95,438.	68,736.	70,083.	10,002.	7,773.	252,032.
3 Gross receipts from activities that are not an unrelated trade or business under section 513			85,512.	86,348.	94,422.	266,282.
4 Tax revenues levied for the organization's benefit and either paid to or expended on its behalf						
5 The value of services or facilities furnished by a governmental unit to the organization without charge						
6 Total. Add lines 1 through 5	2,117,265.	1,905,352.	1,641,166.	1,578,974.	1,504,856.	8,747,613.
7a Amounts included on lines 1, 2, and 3 received from disqualified persons	361,511.	337,622.	329,155.	320,154.	300,175.	1,648,617.
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						0.
c Add lines 7a and 7b	361,511.	337,622.	329,155.	320,154.	300,175.	1,648,617.
8 Public support. (Subtract line 7c from line 6)						7,098,996.

Section B. Total Support

Calendar year (or fiscal year beginning in) ▶	(a) 2008	(b) 2009	(c) 2010	(d) 2011	(e) 2012	(f) Total
9 Amounts from line 6	2,117,265.	1,905,352.	1,641,166.	1,578,974.	1,504,856.	8,747,613.
10a Gross income from interest, dividends, payments received on securities loans, rents, royalties and income from similar sources	47,627.	42,201.	44,473.	44,785.	42,547.	221,633.
b Unrelated business taxable income (less section 511 taxes) from businesses acquired after June 30, 1975						
c Add lines 10a and 10b	47,627.	42,201.	44,473.	44,785.	42,547.	221,633.
11 Net income from unrelated business activities not included in line 10b, whether or not the business is regularly carried on						
12 Other income. Do not include gain or loss from the sale of capital assets (Explain in Part IV.)						
13 Total support. (Add lines 9, 10c, 11, and 12)	2,164,892.	1,947,553.	1,685,639.	1,623,759.	1,547,403.	8,969,246.
14 First five years. If the Form 990 is for the organization's first, second, third, fourth, or fifth tax year as a section 501(c)(3) organization, check this box and stop here ▶ <input type="checkbox"/>						

Section C. Computation of Public Support Percentage

15 Public support percentage for 2012 (line 8, column (f) divided by line 13, column (f))	15	79.15 %
16 Public support percentage from 2011 Schedule A, Part III, line 15	16	79.44 %

Section D. Computation of Investment Income Percentage

17 Investment income percentage for 2012 (line 10c, column (f) divided by line 13, column (f))	17	2.47 %
18 Investment income percentage from 2011 Schedule A, Part III, line 17	18	2.67 %

- 19a **33 1/3% support tests - 2012.** If the organization did not check the box on line 14, and line 15 is more than 33 1/3%, and line 17 is not more than 33 1/3%, check this box and **stop here.** The organization qualifies as a publicly supported organization ▶ ☒
- b **33 1/3% support tests - 2011.** If the organization did not check a box on line 14 or line 19a, and line 16 is more than 33 1/3%, and line 18 is not more than 33 1/3%, check this box and **stop here.** The organization qualifies as a publicly supported organization ▶ ☐
- 20 **Private foundation.** If the organization did not check a box on line 14, 19a, or 19b, check this box and see instructions ▶ ☐

SCHEDULE C
(Form 990 or 990-EZ)

Department of the Treasury
Internal Revenue Service

Political Campaign and Lobbying Activities

For Organizations Exempt From Income Tax Under section 501(c) and section 527

OMB No 1545-0047

2012

**Open to Public
Inspection**

▶ **Complete if the organization is described below. ▶ Attach to Form 990 or Form 990-EZ.**
▶ **See separate instructions.**

If the organization answered "Yes," to Form 990, Part IV, line 3, or Form 990-EZ, Part V, line 46 (Political Campaign Activities), then

- Section 501(c)(3) organizations: Complete Parts I-A and B. Do not complete Part I-C.
- Section 501(c) (other than section 501(c)(3)) organizations: Complete Parts I-A and C below. Do not complete Part I-B.
- Section 527 organizations: Complete Part I-A only.

If the organization answered "Yes," to Form 990, Part IV, line 4, or Form 990-EZ, Part VI, line 47 (Lobbying Activities), then

- Section 501(c)(3) organizations that have filed Form 5768 (election under section 501(h)): Complete Part II-A. Do not complete Part II-B.
- Section 501(c)(3) organizations that have NOT filed Form 5768 (election under section 501(h)): Complete Part II-B. Do not complete Part II-A.

If the organization answered "Yes," to Form 990, Part IV, line 5 (Proxy Tax), or Form 990-EZ, Part V, line 35c (Proxy Tax), then

- Section 501(c)(4), (5), or (6) organizations: Complete Part III.

Name of organization

OSTEOGENESIS IMPERFECTA FOUNDATION, INC.

Employer identification number

23-7076021

Part I-A Complete if the organization is exempt under section 501(c) or is a section 527 organization.

- 1 Provide a description of the organization's direct and indirect political campaign activities in Part IV.
- 2 Political expenditures ▶ \$
- 3 Volunteer hours

Part I-B Complete if the organization is exempt under section 501(c)(3).

- 1 Enter the amount of any excise tax incurred by the organization under section 4955 ▶ \$
- 2 Enter the amount of any excise tax incurred by organization managers under section 4955 ▶ \$
- 3 If the organization incurred a section 4955 tax, did it file Form 4720 for this year? ☐ Yes ☐ No
- 4a Was a correction made? ☐ Yes ☐ No
- b If "Yes," describe in Part IV.

Part I-C Complete if the organization is exempt under section 501(c), except section 501(c)(3).

- 1 Enter the amount directly expended by the filing organization for section 527 exempt function activities ▶ \$
- 2 Enter the amount of the filing organization's funds contributed to other organizations for section 527 exempt function activities ▶ \$
- 3 Total exempt function expenditures. Add lines 1 and 2. Enter here and on Form 1120-POL, line 17b ▶ \$ ☐ Yes ☐ No
- 4 Did the filing organization file **Form 1120-POL** for this year?
- 5 Enter the names, addresses and employer identification number (EIN) of all section 527 political organizations to which the filing organization made payments. For each organization listed, enter the amount paid from the filing organization's funds. Also enter the amount of political contributions received that were promptly and directly delivered to a separate political organization, such as a separate segregated fund or a political action committee (PAC). If additional space is needed, provide information in Part IV.

(a) Name	(b) Address	(c) EIN	(d) Amount paid from filing organization's funds. If none, enter -0-	(e) Amount of political contributions received and promptly and directly delivered to a separate political organization. If none, enter -0-

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

Schedule C (Form 990 or 990-EZ) 2012

LHA

232041
01-07-13

Part II-A Complete if the organization is exempt under section 501(c)(3) and filed Form 5768 (election under section 501(h)).

A Check ☐ if the filing organization belongs to an affiliated group (and list in Part IV each affiliated group member's name, address, EIN, expenses, and share of excess lobbying expenditures).

B Check ☐ if the filing organization checked box A and "limited control" provisions apply.

Limits on Lobbying Expenditures
(The term "expenditures" means amounts paid or incurred.)

(a) Filing organization's totals

(b) Affiliated group totals

1 a Total lobbying expenditures to influence public opinion (grass roots lobbying)**b** Total lobbying expenditures to influence a legislative body (direct lobbying)**c** Total lobbying expenditures (add lines 1a and 1b)**d** Other exempt purpose expenditures**e** Total exempt purpose expenditures (add lines 1c and 1d)**f** Lobbying nontaxable amount. Enter the amount from the following table in both columns.

If the amount on line 1e, column (a) or (b) is:	The lobbying nontaxable amount is:
Not over \$500,000	20% of the amount on line 1e.
Over \$500,000 but not over \$1,000,000	\$100,000 plus 15% of the excess over \$500,000.
Over \$1,000,000 but not over \$1,500,000	\$175,000 plus 10% of the excess over \$1,000,000.
Over \$1,500,000 but not over \$17,000,000	\$225,000 plus 5% of the excess over \$1,500,000.
Over \$17,000,000	\$1,000,000.

g Grassroots nontaxable amount (enter 25% of line 1f)**h** Subtract line 1g from line 1a. If zero or less, enter -0-**i** Subtract line 1f from line 1c. If zero or less, enter -0-**j** If there is an amount other than zero on either line 1h or line 1i, did the organization file Form 4720 reporting section 4911 tax for this year?☐ Yes☐ No**4-Year Averaging Period Under Section 501(h)**

(Some organizations that made a section 501(h) election do not have to complete all of the five columns below. See the instructions for lines 2a through 2f on page 4.)

Lobbying Expenditures During 4-Year Averaging Period

Calendar year (or fiscal year beginning in)	(a) 2009	(b) 2010	(c) 2011	(d) 2012	(e) Total
2a Lobbying nontaxable amount					
b Lobbying ceiling amount (150% of line 2a, column (e))					
c Total lobbying expenditures					
d Grassroots nontaxable amount					
e Grassroots ceiling amount (150% of line 2d, column (e))					
f Grassroots lobbying expenditures					

Schedule C (Form 990 or 990-EZ) 2012

Part II-B Complete if the organization is exempt under section 501(c)(3) and has NOT filed Form 5768 (election under section 501(h)).

For each "Yes," response to lines 1a through 1i below, provide in Part IV a detailed description of the lobbying activity.

	(a)		(b)
	Yes	No	Amount
1 During the year, did the filing organization attempt to influence foreign, national, state or local legislation, including any attempt to influence public opinion on a legislative matter or referendum, through the use of:			
a Volunteers?		X	
b Paid staff or management (include compensation in expenses reported on lines 1c through 1i)?		X	
c Media advertisements?		X	
d Mailings to members, legislators, or the public?		X	
e Publications, or published or broadcast statements?		X	
f Grants to other organizations for lobbying purposes?		X	
g Direct contact with legislators, their staffs, government officials, or a legislative body?		X	
h Rallies, demonstrations, seminars, conventions, speeches, lectures, or any similar means?		X	
i Other activities?	X		20,304.
j Total. Add lines 1c through 1i			20,304.
2a Did the activities in line 1 cause the organization to be not described in section 501(c)(3)?		X	
b If "Yes," enter the amount of any tax incurred under section 4912			
c If "Yes," enter the amount of any tax incurred by organization managers under section 4912			
d If the filing organization incurred a section 4912 tax, did it file Form 4720 for this year?			

Part III-A Complete if the organization is exempt under section 501(c)(4), section 501(c)(5), or section 501(c)(6).

	Yes	No
1 Were substantially all (90% or more) dues received nondeductible by members?		
2 Did the organization make only in-house lobbying expenditures of \$2,000 or less?		
3 Did the organization agree to carry over lobbying and political expenditures from the prior year?		

Part III-B Complete if the organization is exempt under section 501(c)(4), section 501(c)(5), or section 501(c)(6) and if either (a) BOTH Part III-A, lines 1 and 2, are answered "No," OR (b) Part III-A, line 3, is answered "Yes."

1 Dues, assessments and similar amounts from members	1	
2 Section 162(e) nondeductible lobbying and political expenditures (do not include amounts of political expenses for which the section 527(f) tax was paid).		
a Current year	2a	
b Carryover from last year	2b	
c Total	2c	
3 Aggregate amount reported in section 6033(e)(1)(A) notices of nondeductible section 162(e) dues	3	
4 If notices were sent and the amount on line 2c exceeds the amount on line 3, what portion of the excess does the organization agree to carryover to the reasonable estimate of nondeductible lobbying and political expenditure next year?	4	
5 Taxable amount of lobbying and political expenditures (see instructions)	5	

Part IV Supplemental Information

Complete this part to provide the descriptions required for Part I-A, line 1; Part I-B, line 4; Part I-C, line 5; Part II-A (affiliated group list); Part II-A, line 2; and Part II-B, line 1. Also, complete this part for any additional information.

PART II-B, LINE 1, LOBBYING ACTIVITIES:

THE FOUNDATION ADVOCACY EFFORTS FOCUS ON EDUCATING LEGISLATORS AND THEIR STAFFS ABOUT OI AND THE PRIORITIES OF THE FOUNDATION IN ADDITION TO ADVOCATING FOR INCREASED FUNDING FROM THE NATIONAL INSTITUTE OF HEALTH (NIH) FOR OI RESEARCH.

SCHEDULE D
(Form 990)

Department of the Treasury
Internal Revenue Service

Supplemental Financial Statements

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

OMB No 1545-0047

2012

Open to Public Inspection

Name of the organization

OSTEOGENESIS IMPERFECTA FOUNDATION, INC.

Employer identification number

23-7076021

Part I

Organizations Maintaining Donor Advised Funds or Other Similar Funds or Accounts. Complete if the

organization answered "Yes" to Form 990, Part IV, line 6.

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

Part II

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

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

<input type="checkbox"/> Preservation of land for public use (e.g., recreation or education)	<input type="checkbox"/> Preservation of an historically important land area
<input type="checkbox"/> Protection of natural habitat	<input type="checkbox"/> Preservation of a certified historic structure
<input type="checkbox"/> Preservation of open space	

2 Complete lines 2a through 2d if the organization held a qualified conservation contribution in the form of a conservation easement on the last day of the tax year

	Held at the End of the Tax Year
a Total number of conservation easements	2a
b Total acreage restricted by conservation easements	2b
c Number of conservation easements on a certified historic structure included in (a)	2c
d Number of conservation easements included in (c) acquired after 8/17/06, and not on a historic structure listed in the National Register	2d

3 Number of conservation easements modified, transferred, released, extinguished, or terminated by the organization during the tax year ▶

4 Number of states where property subject to conservation easement is located ▶

5 Does the organization have a written policy regarding the periodic monitoring, inspection, handling of violations, and enforcement of the conservation easements it holds? ☐ Yes ☐ No

6 Staff and volunteer hours devoted to monitoring, inspecting, and enforcing conservation easements during the year ▶

7 Amount of expenses incurred in monitoring, inspecting, and enforcing conservation easements during the year ▶ \$

8 Does each conservation easement reported on line 2(d) above satisfy the requirements of section 170(h)(4)(B)(i) and section 170(h)(4)(B)(ii)? ☐ Yes ☐ No

9 In Part XIII, describe how the organization reports conservation easements in its revenue and expense statement, and balance sheet, and include, if applicable, the text of the footnote to the organization's financial statements that describes the organization's accounting for conservation easements.

Part III

Organizations Maintaining Collections of Art, Historical Treasures, or Other Similar Assets.

Complete if the organization answered "Yes" to Form 990, Part IV, line 8.

1a If the organization elected, as permitted under SFAS 116 (ASC 958), not to report in its revenue statement and balance sheet works of art, historical treasures, or other similar assets held for public exhibition, education, or research in furtherance of public service, provide, in Part XIII, the text of the footnote to its financial statements that describes these items.

b If the organization elected, as permitted under SFAS 116 (ASC 958), to report in its revenue statement and balance sheet works of art, historical treasures, or other similar assets held for public exhibition, education, or research in furtherance of public service, provide the following amounts relating to these items:

(i) Revenues included in Form 990, Part VIII, line 1	▶ \$
(ii) Assets included in Form 990, Part X	▶ \$

2 If the organization received or held works of art, historical treasures, or other similar assets for financial gain, provide the following amounts required to be reported under SFAS 116 (ASC 958) relating to these items:

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

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

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

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

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

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

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

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

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

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

	Amount
1c	
1d	
1e	
1f	

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

b If "Yes," explain the arrangement in Part XIII. Check here if the explanation has been provided in Part XIII ☐

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

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

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

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

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

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

- (i) unrelated organizations
 (ii) related organizations

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

	Yes	No
3a(i)		
3a(ii)		
3b		

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

Part VI Land, Buildings, and Equipment. See Form 990, Part X, line 10.

Description of property	(a) Cost or other basis (investment)	(b) Cost or other basis (other)	(c) Accumulated depreciation	(d) Book value
1a Land				
b Buildings				
c Leasehold improvements				
d Equipment		58,224.	45,687.	12,537.
e Other		84,525.	71,990.	12,535.
Total. Add lines 1a through 1e. (Column (d) must equal Form 990, Part X, column (B), line 10(c).)				25,072.

Schedule D (Form 990) 2012

Part VII Investments - Other Securities. See Form 990, Part X, line 12.

(a) Description of security or category (including name of security)	(b) Book value	(c) Method of valuation: Cost or end-of-year market value
(1) Financial derivatives		
(2) Closely-held equity interests		
(3) Other		
(A)		
(B)		
(C)		
(D)		
(E)		
(F)		
(G)		
(H)		
(I)		
Total. (Col. (b) must equal Form 990, Part X, col. (B) line 12.) ►		

Part VIII Investments - Program Related. See Form 990, Part X, line 13.

(a) Description of investment type	(b) Book value	(c) Method of valuation: Cost or end-of-year market value
(1)		
(2)		
(3)		
(4)		
(5)		
(6)		
(7)		
(8)		
(9)		
(10)		
Total. (Col. (b) must equal Form 990, Part X, col. (B) line 13.) ►		

Part IX Other Assets. See Form 990, Part X, line 15.

(a) Description	(b) Book value
(1)	
(2)	
(3)	
(4)	
(5)	
(6)	
(7)	
(8)	
(9)	
(10)	
Total. (Column (b) must equal Form 990, Part X, col. (B) line 15.) ►	

Part X Other Liabilities. See Form 990, Part X, line 25.

1. (a) Description of liability	(b) Book value
(1) Federal income taxes	
(2) DEFERRED RENT	5,563.
(3)	
(4)	
(5)	
(6)	
(7)	
(8)	
(9)	
(10)	
(11)	
Total. (Column (b) must equal Form 990, Part X, col. (B) line 25.) ►	

2. FIN 48 (ASC 740) Footnote. In Part XIII, provide the text of the footnote to the organization's financial statements that reports the organization's liability for uncertain tax positions under FIN 48 (ASC 740). Check here if the text of the footnote has been provided in Part XIII ☒

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

1	Total revenue, gains, and other support per audited financial statements	1	1,745,389.
2	Amounts included on line 1 but not on Form 990, Part VIII, line 12:		
a	Net unrealized gains on investments	2a	191,054.
b	Donated services and use of facilities	2b	10,509.
c	Recoveries of prior year grants	2c	
d	Other (Describe in Part XIII.)	2d	94,422.
e	Add lines 2a through 2d	2e	295,985.
3	Subtract line 2e from line 1	3	1,449,404.
4	Amounts included on Form 990, Part VIII, line 12, but not on line 1:		
a	Investment expenses not included on Form 990, Part VIII, line 7b	4a	
b	Other (Describe in Part XIII.)	4b	88.
c	Add lines 4a and 4b	4c	88.
5	Total revenue. Add lines 3 and 4c . (This must equal Form 990, Part I, line 12.)	5	1,449,492.

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

1	Total expenses and losses per audited financial statements	1	1,757,318.
2	Amounts included on line 1 but not on Form 990, Part IX, line 25:		
a	Donated services and use of facilities	2a	10,509.
b	Prior year adjustments	2b	
c	Other losses	2c	
d	Other (Describe in Part XIII.)	2d	94,422.
e	Add lines 2a through 2d	2e	104,931.
3	Subtract line 2e from line 1	3	1,652,387.
4	Amounts included on Form 990, Part IX, line 25, but not on line 1:		
a	Investment expenses not included on Form 990, Part VIII, line 7b	4a	
b	Other (Describe in Part XIII.)	4b	88.
c	Add lines 4a and 4b	4c	88.
5	Total expenses. Add lines 3 and 4c . (This must equal Form 990, Part I, line 18.)	5	1,652,475.

Part XIII Supplemental Information

Complete this part to provide the descriptions required for Part II, lines 3, 5, and 9; Part III, lines 1a and 4; Part IV, lines 1b and 2b; Part V, line 4; Part X, line 2; Part XI, lines 2d and 4b; and Part XII, lines 2d and 4b. Also complete this part to provide any additional information.

PART X, LINE 2: THE FOUNDATION HAS NO UNCERTAIN TAX POSITIONS THAT

QUALIFY FOR EITHER RECOGNITION OR DISCLOSURE IN THE FINANCIAL STATEMENTS,

AND NO INTEREST AND PENALTIES HAVE BEEN RECORDED IN THE ACCOMPANYING

FINANCIAL STATEMENTS RELATED TO UNCERTAIN TAX POSITIONS.

PART XI, LINE 2D - OTHER ADJUSTMENTS:

SPECIAL EVENT EXPENSES 94,422.

Part XIII Supplemental Information (continued)

PART XI, LINE 4B - OTHER ADJUSTMENTS:

LOSS ON DISPOSITION OF ASSETS 88.

PART XII, LINE 2D - OTHER ADJUSTMENTS:

SPECIAL EVENT EXPENSES 94,422.

PART XII, LINE 4B - OTHER ADJUSTMENTS:

LOSS ON DISPOSITION OF ASSETS 88.

**SCHEDULE F
(Form 990)**Department of the Treasury
Internal Revenue Service**Statement of Activities Outside the United States**▶ Complete if the organization answered "Yes" to Form 990,
Part IV, line 14b, 15, or 16.

▶ Attach to Form 990. ▶ See separate instructions.

OMB No 1545-0047

2012**Open to Public
Inspection**

Name of the organization

Employer identification number

OSTEOGENESIS IMPERFECTA FOUNDATION, INC.

23-7076021

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

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

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

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

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

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

Schedule F (Form 990) 2012

Part IV Foreign Forms

- 1 Was the organization a U.S. transferor of property to a foreign corporation during the tax year? If "Yes," the organization may be required to file Form 926, Return by a U.S. Transferor of Property to a Foreign Corporation (see Instructions for Form 926) ☐ Yes ☒ No
- 2 Did the organization have an interest in a foreign trust during the tax year? If "Yes," the organization may be required to file Form 3520, Annual Return to Report Transactions with Foreign Trusts and Receipt of Certain Foreign Gifts, and/or Form 3520-A, Annual Information Return of Foreign Trust With a U.S. Owner (see Instructions for Forms 3520 and 3520-A) ☐ Yes ☒ No
- 3 Did the organization have an ownership interest in a foreign corporation during the tax year? If "Yes," the organization may be required to file Form 5471, Information Return of U.S. Persons With Respect To Certain Foreign Corporations (see Instructions for Form 5471) ☐ Yes ☒ No
- 4 Was the organization a direct or indirect shareholder of a passive foreign investment company or a qualified electing fund during the tax year? If "Yes," the organization may be required to file Form 8621, Information Return by a Shareholder of a Passive Foreign Investment Company or Qualified Electing Fund (see Instructions for Form 8621) ☐ Yes ☒ No
- 5 Did the organization have an ownership interest in a foreign partnership during the tax year? If "Yes," the organization may be required to file Form 8865, Return of U.S. Persons With Respect To Certain Foreign Partnerships. (see Instructions for Form 8865) ☐ Yes ☒ No
- 6 Did the organization have any operations in or related to any boycotting countries during the tax year? If "Yes," the organization may be required to file Form 5713, International Boycott Report. (see Instructions for Form 5713) ☐ Yes ☒ No

Schedule F (Form 990) 2012

Part V **Supplemental Information**

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

SCHEDULE F, PART I, LINE 2: THE FOUNDATION RECEIVES REPORTS FROM THE
GRANTEE LISTING THE AMOUNTS THAT HAVE BEEN SPENT ON GRANT RESEARCH. ONCE
THE SPENDING REPORTS ARE APPROVED BY THE FOUNDATION, THE GRANTEE WILL
RECEIVE THE AWARDED FUNDS.

Department of the Treasury
Internal Revenue Service

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

2012

Open To Public Inspection

Employer identification number
23-7076021

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

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

- ☐
- Yes
- ☐
- No

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

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

Part II Fundraising Events. Complete if the organization answered "Yes" to Form 990, Part IV, line 18, or reported more than \$15,000 of fundraising event contributions and gross income on Form 990-EZ, lines 1 and 6b. List events with gross receipts greater than \$5,000.

		(a) Event #1	(b) Event #2	(c) Other events	(d) Total events (add col. (a) through col. (c))
		SCPICA GOLF TOURNAMENT (event type)	JADEN'S SWIM (event type)	13 (total number)	
Revenue	1 Gross receipts	51,000.	122,306.	344,511.	517,817.
	2 Less: Contributions	51,000.	122,306.	250,089.	423,395.
	3 Gross income (line 1 minus line 2)			94,422.	94,422.
Direct Expenses	4 Cash prizes				
	5 Noncash prizes				
	6 Rent/facility costs				
	7 Food and beverages				
	8 Entertainment				
	9 Other direct expenses			94,422.	94,422.
	10 Direct expense summary. Add lines 4 through 9 in column (d)				(94,422)
	11 Net income summary. Combine line 3, column (d), and line 10				0.

Part III Gaming. Complete if the organization answered "Yes" to Form 990, Part IV, line 19, or reported more than \$15,000 on Form 990-EZ, line 6a.

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

9 Enter the state(s) in which the organization operates gaming activities: _____**a** Is the organization licensed to operate gaming activities in each of these states? ☐ Yes ☐ No**b** If "No," explain: _____**10a** Were any of the organization's gaming licenses revoked, suspended or terminated during the tax year? ☐ Yes ☐ No**b** If "Yes," explain: _____

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

Name ▶ _____

Address ▶ _____

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

Name ▶ _____

Address ▶ _____

16 Gaming manager information:

Name ▶ _____

Gaming manager compensation ▶ \$ _____

Description of services provided ▶ _____

☐ Director/officer☐ Employee☐ Independent contractor**17** Mandatory distributions:**a** Is the organization required under state law to make charitable distributions from the gaming proceeds to retain the state gaming license? ☐ Yes ☐ No**b** Enter the amount of distributions required under state law to be distributed to other exempt organizations or spent in the organization's own exempt activities during the tax year ▶ \$ _____**Part IV** **Supplemental Information.** Complete this part to provide the explanations required by Part I, line 2b, columns (iii) and (v), and Part III, lines 9, 9b, 10b, 15b, 15c, 16, and 17b, as applicable. Also complete this part to provide any additional information (see instructions).

SCHEDULE I
(Form 990)

Department of the Treasury
Internal Revenue Service

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

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

OMB No 1545-0047

2012

Open to Public
Inspection

Name of the organization

OSTEOGENESIS IMPERFECTA FOUNDATION, INC.

Employer identification number
23-7076021

Part I General Information on Grants and Assistance

1 Does the organization maintain records to substantiate the amount of the grants or assistance, the grantees' eligibility for the grants or assistance, and the selection criteria used to award the grants or assistance?

☒ Yes ☐ No

2 Describe in Part IV the organization's procedures for monitoring the use of grant funds in the United States.

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

1 (a) Name and address of organization or government	(b) EIN	(c) IRC section if applicable	(d) Amount of cash grant	(e) Amount of non-cash assistance	(f) Method of valuation (book, FMV, appraisal, other)	(g) Description of non-cash assistance	(h) Purpose of grant or assistance
SHRINERS HOSPITAL FOR CHILDREN 2111 N OAK PARK AVENUE CHICAGO, IL 60707	04-2121377	501C3	17,200.	0.			LINKED CLINICAL RESEARCH CENTER GRANT
BAYLOR COLLEGE OF MEDICINE ONE BAYLOR PLAZA HOUSTON, TX 77030	74-1613878	501C3	50,000.	0.			FELLOWSHIP RESEARCH GRANT
KENNEDY KRIEGER INSTITUTE 707 N. BROADWAY BALTIMORE, MD 21205	52-1524965	501C3	14,200.	0.			LINKED CLINICAL RESEARCH CENTER GRANT
BAYLOR COLLEGE OF MEDICINE ONE BAYLOR PLAZA HOUSTON, TX 77030	74-1613878	501C3	6,000.	0.			LINKED CLINICAL RESEARCH CENTER GRANT

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

3 Enter total number of other organizations listed in the line 1 table

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

Schedule I (Form 990) (2012)

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

(a) Type of grant or assistance	(b) Number of recipients	(c) Amount of cash grant	(d) Amount of non-cash assistance	(e) Method of valuation (book, FMV, appraisal, other)	(f) Description of non-cash assistance
ACCESSIBLE VANS PROVIDED TO INDIVIDUALS WITH OSTEOGENESIS IMPERFECTA.	3	0.	78,585.	FAIR MARKET VALUE	VANS
WHEELCHAIR RAMP PROVIDED TO INDIVIDUALS WITH OSTEOGENESIS IMPERFECTA	1	0.	2,999.	FAIR MARKET VALUE	WHEELCHAIR RAMPS
DENTAL PROCEDURES PROVIDED TO INDIVIDUALS WITH OSTEOGENESIS IMPERFECTA.	2	0.	7,671.	FAIR MARKET VALUE	DENTAL PROCEDURES DUE TO THE EFFECTS OF OI
ADAPTIVE EQUIPMENT PROVIDED TO INDIVIDUALS WITH OSTEOGENESIS IMPERFECTA.	7	0.	3,162.	FAIR MARKET VALUE	ACCESSIBILITY AIDS AND ADAPTIVE TECHNOLOGY SUCH AS HEARING AIDS AND COMPUTERS
WHEELCHAIRS AND WALKERS PROVIDED TO INDIVIDUALS WITH OSTEOGENESIS IMPERFECTA.	2	0.	6,092.	FAIR MARKET VALUE	WHEELCHAIRS AND WALKERS

Part IV Supplemental Information. Complete this part to provide the information required in Part I, line 2, Part III, column (b), and any other additional information.

SCHEDULE I, 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.

Part III Continuation of Grants and Other Assistance to Individuals in the United States (Schedule I (Form 990), Part III)

(a) Type of grant or assistance	(b) Number of recipients	(c) Amount of cash grant	(d) Amount of non-cash assistance	(e) Method of valuation (book, FMV, appraisal, other)	(f) Description of non-cash assistance
MEDICAL SUPPLIES, DEVICES, AND HOSPITAL FEES PROVIDED TO INDIVIDUALS WITH OSTEOGENESIS IMPERFECTA.	4.	0.	16,039.	FAIR MARKET VALUE	MEDICAL SUPPLIES, DEVICES, AND HOSPITAL FEES
FINANCIAL SUBSIDY TO FINISH COLLEGE PROVIDED TO INDIVIDUALS WITH OSTEOGENESIS IMPERFECTA.	1.	5,000.	0.	FAIR MARKET VALUE	TUITION

Schedule I (Form 990)

SCHEDULE J
(Form 990)

Department of the Treasury
Internal Revenue Service

Compensation Information

For certain Officers, Directors, Trustees, Key Employees, and Highest Compensated Employees

▶ **Complete if the organization answered "Yes" to Form 990, Part IV, line 23.**

▶ **Attach to Form 990. ▶ See separate instructions.**

OMB No 1545-0047

2012

Open to Public Inspection

Name of the organization

OSTEOGENESIS IMPERFECTA FOUNDATION, INC.

Employer identification number

23-7076021

Part I Questions Regarding Compensation

1a Check the appropriate box(es) if the organization provided any of the following to or for a person listed in Form 990, Part VII, Section A, line 1a. Complete Part III to provide any relevant information regarding these items.

☐ First-class or charter travel

☐ Travel for companions

☐ Tax indemnification and gross-up payments

☐ Discretionary spending account

☐ Housing allowance or residence for personal use

☐ Payments for business use of personal residence

☐ Health or social club dues or initiation fees

☐ Personal services (e.g., maid, chauffeur, chef)

b If any of the boxes on line 1a are checked, did the organization follow a written policy regarding payment or reimbursement or provision of all of the expenses described above? If "No," complete Part III to explain

2 Did the organization require substantiation prior to reimbursing or allowing expenses incurred by all officers, directors, trustees, and the CEO/Executive Director, regarding the items checked in line 1a?

3 Indicate which, if any, of the following the filing organization used to establish the compensation of the organization's CEO/Executive Director. Check all that apply. Do not check any boxes for methods used by a related organization to establish compensation of the CEO/Executive Director, but explain in Part III.

☐ Compensation committee

☐ Independent compensation consultant

☐ Form 990 of other organizations

☒ Written employment contract

☒ Compensation survey or study

☒ Approval by the board or compensation committee

4 During the year, did any person listed in Form 990, Part VII, Section A, line 1a, with respect to the filing organization or a related organization:

a Receive a severance payment or change-of-control payment?

b Participate in, or receive payment from, a supplemental nonqualified retirement plan?

c Participate in, or receive payment from, an equity-based compensation arrangement?

If "Yes" to any of lines 4a-c, list the persons and provide the applicable amounts for each item in Part III.

Only section 501(c)(3) and 501(c)(4) organizations must complete lines 5-9.

5 For persons listed in Form 990, Part VII, Section A, line 1a, did the organization pay or accrue any compensation contingent on the revenues of:

a The organization?

b Any related organization?

If "Yes" to line 5a or 5b, describe in Part III.

6 For persons listed in Form 990, Part VII, Section A, line 1a, did the organization pay or accrue any compensation contingent on the net earnings of:

a The organization?

b Any related organization?

If "Yes" to line 6a or 6b, describe in Part III.

7 For persons listed in Form 990, Part VII, Section A, line 1a, did the organization provide any non-fixed payments not described in lines 5 and 6? If "Yes," describe in Part III

8 Were any amounts reported in Form 990, Part VII, paid or accrued pursuant to a contract that was subject to the initial contract exception described in Regulations section 53.4958-4(a)(3)? If "Yes," describe in Part III

9 If "Yes" to line 8, did the organization also follow the rebuttable presumption procedure described in Regulations section 53.4958-6(c)?

Yes No

1b

2

4a

4b

4c

5a

5b

6a

6b

7

8

9

X

X

X

X

X

X

X

X

X

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

Schedule J (Form 990) 2012

SCHEDULE L
(Form 990 or 990-EZ)

Department of the Treasury
Internal Revenue Service

Transactions With Interested Persons

- ▶ **Complete if the organization answered**
"Yes" on Form 990, Part IV, line 25a, 25b, 26, 27, 28a, 28b, or 28c,
or Form 990-EZ, Part V, line 38a or 40b.
▶ **Attach to Form 990 or Form 990-EZ. ▶ See separate instructions.**

OMB No 1545-0047

2012

**Open To Public
Inspection**

Name of the organization

OSTEOGENESIS IMPERFECTA FOUNDATION, INC.

Employer identification number
23-7076021

Part I Excess Benefit Transactions (section 501(c)(3) and section 501(c)(4) organizations only).

Complete if the organization answered "Yes" on Form 990, Part IV, line 25a or 25b, or Form 990-EZ, Part V, line 40b.

1	(a) Name of disqualified person	(b) Relationship between disqualified person and organization	(c) Description of transaction	(d) Corrected?	
				Yes	No

2 Enter the amount of tax incurred by the organization managers or disqualified persons during the year under section 4958

▶ \$

3 Enter the amount of tax, if any, on line 2, above, reimbursed by the organization

▶ \$

Part II Loans to and/or From Interested Persons.

Complete if the organization answered "Yes" on Form 990-EZ, Part V, line 38a or Form 990, Part IV, line 26; or if the organization reported an amount on Form 990, Part X, line 5, 6, or 22.

(a) Name of interested person	(b) Relationship with organization	(c) Purpose of loan	(d) Loan to or from the organization?		(e) Original principal amount	(f) Balance due	(g) In default?		(h) Approved by board or committee?		(i) Written agreement?	
			To	From			Yes	No	Yes	No	Yes	No

Total

▶ \$

Part III Grants or Assistance Benefiting Interested Persons.

Complete if the organization answered "Yes" on Form 990, Part IV, line 27.

(a) Name of interested person	(b) Relationship between interested person and the organization	(c) Amount of assistance	(d) Type of assistance	(e) Purpose of assistance

(a) Name of interested person

(b) Relationship between interested person and the organization

(c) Amount of transaction

(d) Description of transaction

(e) Sharing of organization's revenues?	
Yes	No

FRANCIS GLORIEUX, M.D. PH.	MEDICAL ADVISORY CH	48,400.	LCRC-AWARDE
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Part V	Supplemental Information
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SCH L, PART IV, BUSINESS TRANSACTIONS INVOLVING INTERESTED PERSONS:

(A) NAME OF INTERESTED PERSON:

FRANCIS GLORIEUX, M.D. PH.D. SHRINERS HOSPITAL MONTREAL

(B) RELATIONSHIP BETWEEN INTERESTED PERSON AND ORGANIZATION:

MEDICAL ADVISORY CHAIR

(D) DESCRIPTION OF TRANSACTION: LCRC-AWARDED BY THE LCRC COMMITTEE

SCHEDULE O
(Form 990 or 990-EZ)

Department of the Treasury
Internal Revenue Service

Supplemental Information to Form 990 or 990-EZ

Complete to provide information for responses to specific questions on
Form 990 or 990-EZ or to provide any additional information.
▶ Attach to Form 990 or 990-EZ.

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OSTEOGENESIS IMPERFECTA FOUNDATION, INC.

Employer identification number
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FORM 990, PART I, LINE 1, DESCRIPTION OF ORGANIZATION MISSION:

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 NATIONAL
CONFERENCE IN WASHINGTON, DC, OI SCIENTIFIC MEETING, RARE BONE DISEASE
ADVOCACY ALLIANCE, AND RARE BONE DISEASE PATIENT NETWORK MEETING WERE
AMONG THE SIGNIFICANT 2013 FISCAL YEAR HIGHLIGHTS.

FORM 990, PART III, LINE 4A, PROGRAM SERVICE ACCOMPLISHMENTS:

THE OI FOUNDATION ALSO CONTINUED SUPPORTING TWO MICHAEL GEISMAN
FELLOWSHIPS. EACH OF THESE STUDIES EXAMINES SPECIFIC GENETIC MUTATIONS
THAT MAY SOMEDAY LEAD TO NEW TREATMENTS TO STRENGTHEN BONES, ONCE THEY
ARE BETTER UNDERSTOOD. BOTH RESEARCHERS HAVE BEEN SUCCESSFUL IN MOVING
THEIR RESEARCH FORWARD. THEIR REPORTS ARE AVAILABLE ON THE OIF
WEBSITE. IN ADDITION THE OI FOUNDATION FUNDED A CLINICAL RESEARCH
GRANT THAT WILL LEAD TO A BETTER UNDERSTANDING OF HEART CONDITIONS OI
INCLUDING HEART VALVE PROBLEMS, PROBLEMS WITH THE AORTA OR OTHER BLOOD
VESSEL PROBLEMS.

THE FOUNDATION, IN PARTNERSHIP WITH THE CHILDREN'S BRITTLE BONE
FOUNDATION (CBBF), SUPPORTS THE LINKED CLINICAL RESEARCH CENTERS (LCRC)
PROJECT. THE PROJECT CONTINUED THIS YEAR AND REACHED AND SURPASSED ITS
ENROLLMENT GOAL OF 500 PEOPLE IN THE NATURAL HISTORY STUDY. THE
ENROLLMENT OF OVER 500 PEOPLE MAKES THE NATURAL HISTORY STUDY VERY

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

Schedule O (Form 990 or 990-EZ) (2012)

232211
01-04-13

Name of the organization

OSTEOGENESIS IMPERFECTA FOUNDATION, INC.

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23-7076021

STRONG AND WILL BE A FOCAL POINT OF GRANT SUBMISSIONS TO CONTINUE THE WORK OF THE LCRC MOVING FORWARD. CURRENTLY INFORMATION FROM THE STUDY IS BEING RELEASED FOR PUBLICATIONS. THIS WORK REPRESENTS A LONG-TERM COMMITMENT TO DEVELOPING EVIDENCE-BASED TREATMENTS FOR OI ACROSS THE ENTIRE LIFESPAN AND INSPIRING CLINICAL CARE RESEARCH. AT THIS TIME, FIVE CENTERS ARE IN OPERATION IN THE UNITED STATES AND CANADA. ALL CONTRIBUTE INFORMATION TO THE CENTRAL DATA MANAGEMENT SYSTEM. A REGISTRY OF PEOPLE WITH OI IS PART OF THIS PROJECT.

FORM 990, PART III, LINE 4B, PROGRAM SERVICE ACCOMPLISHMENTS:

SCHOOL PROFESSIONALS. ON AVERAGE, 25,000 PEOPLE USE THE WEBSITE EACH MONTH. FOUNDATION STAFF AND VOLUNTEERS RESPOND TO MORE THAN 6,500 DIRECT INQUIRIES A YEAR. INFORMATION FROM THESE CONTACTS IS USED TO ASSESS THE NEED FOR NEW RESOURCES. THE OIF WEBSITE WAS VISITED 205,000 TIMES IN SEARCH OF INFORMATION.

THE FOUNDATION SPONSORS A NETWORK OF SUPPORT GROUPS ACROSS THE UNITED STATES. SUPPORT GROUP ACTIVITIES PROVIDE OPPORTUNITIES FOR MUTUAL SUPPORT, AND INCREASED COMMUNITY AWARENESS. CURRENTLY, THERE ARE 41 ACTIVE GROUPS IN 32 STATES. IN ADDITION, 24 VOLUNTEER RESOURCE PEOPLE ARE ACTIVE IN 18 STATES.

IN PARTNERSHIP WITH THE CHILDREN'S BRITTLE BONE FOUNDATION (CBBF) AN ANNUAL COMPETITIVE GRANT PROGRAM HAS BEEN ESTABLISHED. IT IS DESIGNED TO PROVIDE FUNDING FOR ITEMS THAT WILL SIGNIFICANTLY IMPROVE THE QUALITY OF LIFE FOR A PERSON WHO HAS OI AND WHO HAS LIMITED FINANCIAL RESOURCES. LAST YEAR FUNDS WERE AWARDED FOR ITEMS LIKE ADAPTED

VEHICLES, NEW MOBILITY DEVICES, COMPUTERS, HEARING AIDS, DENTAL WORK

Name of the organization

OSTEOGENESIS IMPERFECTA FOUNDATION, INC.

Employer identification number

23-7076021

AND OTHER PRODUCTS AND SERVICES. THE MOST RECENT FUNDING CYCLE BEGIN
IN JANUARY 2013.

FORM 990, PART III, LINE 4C, PROGRAM SERVICE ACCOMPLISHMENTS:

PROCLAMATIONS DECLARING IT OI AWARENESS WEEK AT THE LOCAL AND STATE
LEVELS AND CONTRIBUTED THEIR PERSONAL STORIES TO MORE THAN 20
PUBLICATIONS ACROSS THE COUNTRY.

THE OI FOUNDATION 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 OI FOUNDATION ALSO
MAINTAINS AN OFFICIAL OIF FACEBOOK PAGE THAT PROVIDES INFORMATION AND
RESOURCES TO ALL AGES AND IS UPDATED DAILY.

THE FOUNDATION IS COMMITTED TO ADVOCATING ON BEHALF OF PEOPLE WITH OI
AND HAS ESTABLISHED AN ADVOCACY INITIATIVE. A GRASSROOTS EFFORT
FOCUSES ON EDUCATING LEGISLATORS AND THEIR STAFFS ABOUT OI AND THE
PRIORITIES OF THE FOUNDATION IN ADDITION TO ADVOCATING FOR INCREASED
FUNDING FOR THE NATIONAL INSTITUTES OF HEALTH. IN JULY 2012 MORE THAN
100 OI FOUNDATION VOLUNTEERS TRAVELED TO CAPITOL HILL TO ENCOURAGE
LEGISLATORS TO INCREASE FUNDING FOR NIH RARE BONE DISEASE RELATED
RESEARCH, SPECIFICALLY OI, AND EDUCATED THEM ON WHAT IT MEANS TO LIVE
WITH A RARE AND OFTEN DEBILITATING DISORDER LIKE OI.

FORM 990, PART III, LINE 4D, OTHER PROGRAM SERVICES:

THE FOUNDATION'S PRINCIPAL EDUCATION EVENT IS THE BIENNIAL NATIONAL

Name of the organization

OSTEOGENESIS IMPERFECTA FOUNDATION, INC.

Employer identification number

23-7076021

CONFERENCE ON OI. THE CONFERENCE BRINGS TOGETHER ADULTS WHO HAVE OI, PARENTS, OTHER FAMILY MEMBERS AND LEADING MEDICAL EXPERTS. THIS CONFERENCE PROVIDES THE OPPORTUNITY FOR ATTENDEES TO HAVE FACE-TO-FACE MEETINGS WITH EXPERIENCED PHYSICIANS, LEARN ABOUT THE LATEST RESEARCH AND INTERACT WITH OTHER PEOPLE WHO ARE AFFECTED BY OI. THE JULY 2012 CONFERENCE HAD 700 ATTENDEES. THE THEME OF THE CONFERENCE "AWARENESS, ADVOCACY, ACTION!" ASKED PARTICIPANTS TO HELP THE OI FOUNDATION RAISE AWARENESS BY SHARING THEIR "UNBREAKABLE SPIRIT" IN THEIR COMMUNITY. THE 2012 CONFERENCE ALSO PRESENTED THE FIRST WOMEN'S FORUM, COORDINATED BY TWO BOARD MEMBERS. THE FORUM WAS OPEN TO ONLY WOMEN WITH OI AND EXPLORED ISSUES THAT DIRECTLY AFFECT WOMEN INCLUDING NUTRITION, SEXUALITY, PREGNANCY AND OVERALL WOMEN'S HEALTH. THE FORUM WAS A SUCCESS AND WILL BE REPEATED AT THE 2014 CONFERENCE.

IN APRIL 2013, 70 SCIENTISTS GATHERED FOR THE ANNUAL OIF SCIENTIFIC MEETING. THE MEETING TITLED "MOUSE MODELS FOR DOMINANT AND RECESSIVE OI" EXPLORED THE IDEA OF A GROWING AWARENESS THAT THE SPECIFIC OI MUTATION MAY BE A KEY TO UNDERSTANDING WHY PEOPLE WITH OI RESPOND TO TREATMENTS DIFFERENTLY. THIS WORK IS IMPORTANT BECAUSE LEARNING MORE ABOUT HOW OI WORKS ON A BASIC LEVEL IS ONE WAY TO IDENTIFY POTENTIAL NEW TARGETS FOR TREATMENTS AND WILL ALLOW US TO GET A HEAD START ON TESTING DRUGS OR POTENTIAL DRUGS THAT ARE IN THE VERY EARLIEST STAGES OF DEVELOPMENT.

THE ADULT HEALTH INITIATIVE IS ANOTHER RESEARCH ACTIVITY OF THE OI FOUNDATION. A SURVEY OF ADULTS WITH OI WAS CONDUCTED IN 2011. FOLLOW UP ACTIVITIES INCLUDED PRESENTATIONS AT THE 2012 OIF SCIENCE MEETING AND A SMALL WORKING GROUP MET AT THE 2013 SCIENTIFIC MEETING TO

Name of the organization

OSTEOGENESIS IMPERFECTA FOUNDATION, INC.

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23-7076021

CONTINUE EXAMINING THE NEEDS OF ADULTS WHO HAVE OI AND IDENTIFYING
AREAS NEEDING RESEARCH. THIS IS AN ONGOING PROJECT WITH THE GOAL OF
DEVELOPING CARE GUIDELINES FOR ADULTS WHO HAVE OI.

THE OI FOUNDATION ALSO TOOK THE LEAD ON PRESENTING A WORKING GROUP
MEETING OF THE RARE BONE DISEASE COMMUNITY AT THE OCTOBER 2012 AMERICAN
SOCIETY OF BONE & MINERAL RESEARCH ANNUAL MEETING IN MINNEAPOLIS, MN.
THE WORKING GROUP MEETING, CHAIRED BY MEDICAL ADVISORY COUNCIL MEMBER,
DR. JAY SHAPIRO, CONTINUED THE DISCUSSION ABOUT RARE BONE DISEASE
RESEARCH AND WHY IT IS IMPORTANT TO ALL BONE DISEASE RESEARCH. THE
WORKING GROUP ATTRACTED 75 SCIENTISTS FROM AROUND THE WORLD INTERESTED
IN RARE BONE DISEASE RESEARCH. BECAUSE OF THE LEADERSHIP OF THE OI
FOUNDATION AND THE WORK OF THE RARE BONE DISEASE ORGANIZATIONS, ASBMR
WILL MAKE RARE BONE DISEASE RESEARCH THE PRE-MEETING TOPIC OF THE 2014
ASBMR ANNUAL MEETING. THE PRE-MEETINGS TRADITIONALLY ATTRACT BETWEEN
400 AND 600 ATTENDEES.

EXPENSES \$ 262,884. INCLUDING GRANTS OF \$ 0. REVENUE \$ 0.

FORM 990, PART VI, SECTION A, LINE 6: MEMBERSHIP IN THE OI FOUNDATION IS
OPEN TO ALL PEOPLE WHO SUPPORT THE MISSION OF THE OI FOUNDATION. THE BOARD
OF DIRECTORS DETERMINE THE LEVEL AND BENEFITS OF MEMBERSHIP, AND MAY CHANGE
THESE FROM TIME TO TIME. ALL MEMBERS ARE ENTITLED TO VOTING PRIVILEGES.
MEMBERSHIP BECOMES EFFECTIVE UPON RECEIPT OF DUES.

FORM 990, PART VI, SECTION B, LINE 11: AFTER THE FORM 990 IS PREPARED BY
INDEPENDENT ACCOUNTANTS IT IS REVIEWED BY THE AUDIT COMMITTEE BEFORE BEING
FILED WITH THE IRS.

FORM 990, PART VI, SECTION B, LINE 12C: THE CONFLICT OF INTEREST POLICY

Name of the organization

OSTEOGENESIS IMPERFECTA FOUNDATION, INC.

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23-7076021

COVERS ALL MEMBERS OF THE BOARD, ITS COMMITTEES, FOUNDATION STAFF AND THEIR IMMEDIATE FAMILIES AND BUSINESS ASSOCIATES. IT IS MONITORED BY ANNUAL WRITTEN 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 (PAST, 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 RECUSALS ARE DOCUMENTED IN THE MINUTES OF EACH BOARD OR COMMITTEE MEETING.

FORM 990, PART VI, SECTION B, LINE 15A: THE PROCESS FOR DETERMINING COMPENSATION OF THE FOLLOWING PERSONS INCLUDES A REVIEW AND APPROVAL BY INDEPENDENT MEMBERS OF THE EXECUTIVE COMMITTEE. COMPARABILITY DATA USED IN THE REVIEW PROCESS IS OBTAINED FROM NATIONAL HEALTH COUNCIL SALARY SURVEY. THE DELIBERATIONS AND DECISIONS ARE DOCUMENTED IN THE MINUTES OF THE BOARD OR COMMITTEE MEETING. THE COMPENSATION DETERMINATION PROCESS APPLIES TO THE FOLLOWING OFFICES/POSITIONS AND THE MOST RECENT YEAR FOR WHICH THIS PROCESS WAS UNDERTAKEN FOR EACH IS IDENTIFIED:

OFFICE/TITLE	YEAR OF MOST RECENT REVIEW/APPROVAL
CHEIF EXECUTIVE OFFICER	2012

FORM 990, PART VI, LINE 17, LIST OF STATES RECEIVING COPY OF FORM 990:
 AK, AZ, AR, CA, CO, CT, DC, FL, GA, IL, KS, KY, ME, MD, MA, MI, MN, MS, NH, NJ, NM, NY, NC, ND, OH
 OK, OR, PA, RI, SC, SD, TN, UT, VT, VA, WA, WV, WI, IA

FORM 990, PART VI, SECTION C, LINE 19: OI FOUNDATION MAKES ITS GOVERNING

Name of the organization

OSTEOGENESIS IMPERFECTA FOUNDATION, INC.

Employer identification number

23-7076021

DOCUMENTS, CONFLICT OF INTEREST POLICY, AND FINANCIAL STATEMENTS AVAILABLE
TO THE PUBLIC ON THEIR WEBSITE.

FORM 990, PART XI, LINE 2C:

NO CHANGES FROM THE PRIOR YEAR.

Application for Extension of Time To File an Exempt Organization Return

OMB No. 1545-1709

► **File a separate application for each return.**

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

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

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

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

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

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

Type or print	Name of exempt organization or other filer, see instructions.	Employer identification number (EIN) or
	OSTEOGENESIS IMPERFECTA FOUNDATION, INC.	23-7076021
	Number, street, and room or suite no. If a P.O. box, see instructions. 804 W. DIAMOND AVENUE, NO. 210	Social security number (SSN)
File by the due date for filing your return. See instructions	City, town or post office, state, and ZIP code. For a foreign address, see instructions. GAITHERSBURG, MD 20878	

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

01

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

THE FOUNDATION

- The books are in the care of ► 804 W. DIAMOND AVE, SUITE 210 - GAITHERSBURG, MD 20878
Telephone No. ► 301-947-0083 FAX No. ►

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

- 1 I request an automatic 3-month (6 months for a corporation required to file Form 990-T) extension of time until **FEBRUARY 15, 2014**, to file the exempt organization return for the organization named above. The extension is for the organization's return for:
- ☐ calendar year _____ or
- ☒ tax year beginning **JUL 1, 2012**, and ending **JUN 30, 2013**.

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

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

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

LHA For Privacy Act and Paperwork Reduction Act Notice, see instructions.

Form 8868 (Rev. 1-2013)