

Short Form

Return of Organization Exempt From Income Tax

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

2019

Open to Public Inspection

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

Go to www.irs.gov/Form990EZ for instructions and the latest information.

Department of the Treasury Internal Revenue Service

A For the 2019 calendar year, or tax year beginning, 2019, and ending, 20

B Check if applicable: Address change, Name change, Initial return, Final return/terminated, Amended return, Application pending. C Name of organization: International Sacral Agenesis/Caudal Regression Association (ISACRA). D Employer identification number: 45-564733. E Telephone number: 6316295277. F Group Exemption Number.

G Accounting Method: Cash. I Website: www.isacra.org. H Check if the organization is not required to attach Schedule B.

J Tax-exempt status (check only one) - 501(c)(3). K Form of organization: Corporation.

L Add lines 5b, 6c, and 7b to line 9 to determine gross receipts. If gross receipts are \$200,000 or more, or if total assets (Part II, column (B)) are \$500,000 or more, file Form 990 instead of Form 990-EZ.

Part I Revenue, Expenses, and Changes in Net Assets or Fund Balances (see the instructions for Part I) Check if the organization used Schedule O to respond to any question in this Part I

Table with 21 rows and 3 columns. Rows include Revenue (1-9), Expenses (10-17), and Net Assets (18-21). Values range from 0 to 6212.83.

Part II Balance Sheets (see the instructions for Part II)

Check if the organization used Schedule O to respond to any question in this Part II [checked]

Table with 3 columns: Description, (A) Beginning of year, (B) End of year. Rows include Cash, savings, and investments; Land and buildings; Other assets; Total assets; Total liabilities; Net assets or fund balances.

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

Check if the organization used Schedule O to respond to any question in this Part III [checked]

What is the organization's primary exempt purpose? support and inform those with SA/CRS and families

Describe the organization's program service accomplishments for each of its three largest program services, as measured by expenses. In a clear and concise manner, describe the services provided, the number of persons benefited, and other relevant information for each program title.

Expenses (Required for section 501(c)(3) and 501(c)(4) organizations; optional for others.)

Table with 3 columns: Description, Amount, Expense Code. Rows include support attendance at conferences and events for and about those with rare disorders (NORD); maintain informative robust website and resources; provide college scholarships to students with sa/crs; Other program services; Total program service expenses.

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

Check if the organization used Schedule O to respond to any question in this Part IV [unchecked]

Table with 5 columns: (a) Name and title, (b) Average hours per week devoted to position, (c) Reportable compensation, (d) Health benefits, contributions to employee benefit plans, and deferred compensation, (e) Estimated amount of other compensation. Rows include Leah Balent (President), Melissa Ann Lackey (Treasurer), Kendra Houser (Vice President), Heather Doyan (Secretary), Phyllis Rogers (Executive Director).

Part V Other Information (Note the Schedule A and personal benefit contract statement requirements in the instructions for Part V.) Check if the organization used Schedule O to respond to any question in this Part V

		Yes	No
33	Did the organization engage in any significant activity not previously reported to the IRS? If "Yes," provide a detailed description of each activity in Schedule O . . . . .		✓
34	Were any significant changes made to the organizing or governing documents? If "Yes," attach a conformed copy of the amended documents if they reflect a change to the organization's name. Otherwise, explain the change on Schedule O. See instructions . . . . .		✓
35a	Did the organization have unrelated business gross income of \$1,000 or more during the year from business activities (such as those reported on lines 2, 6a, and 7a, among others)? . . . . .		✓
b	If "Yes" to line 35a, has the organization filed a Form 990-T for the year? If "No," provide an explanation in Schedule O . . . . .		
35b	Was the organization a section 501(c)(4), 501(c)(5), or 501(c)(6) organization subject to section 6033(e) notice, reporting, and proxy tax requirements during the year? If "Yes," complete Schedule C, Part III . . . . .		
35c			
36	Did the organization undergo a liquidation, dissolution, termination, or significant disposition of net assets during the year? If "Yes," complete applicable parts of Schedule N . . . . .		✓
37a	Enter amount of political expenditures, direct or indirect, as described in the instructions ▶ <u>37a</u> 0		
b	Did the organization file Form 1120-POL for this year? . . . . .		✓
38a	Did the organization borrow from, or make any loans to, any officer, director, trustee, or key employee; or were any such loans made in a prior year and still outstanding at the end of the tax year covered by this return? . . . . .		✓
b	If "Yes," complete Schedule L, Part II, and enter the total amount involved . . . . .		
38b			
39	Section 501(c)(7) organizations. Enter:		
a	Initiation fees and capital contributions included on line 9 . . . . .		
39a			
b	Gross receipts, included on line 9, for public use of club facilities . . . . .		
39b			
40a	Section 501(c)(3) organizations. Enter amount of tax imposed on the organization during the year under: section 4911 ▶ _____; section 4912 ▶ _____; section 4955 ▶ _____		
b	Section 501(c)(3), 501(c)(4), and 501(c)(29) organizations. Did the organization engage in any section 4958 excess benefit transaction during the year, or did it engage in an excess benefit transaction in a prior year that has not been reported on any of its prior Forms 990 or 990-EZ? If "Yes," complete Schedule L, Part I . . . . .		✓
40b			
c	Section 501(c)(3), 501(c)(4), and 501(c)(29) organizations. Enter amount of tax imposed on organization managers or disqualified persons during the year under sections 4912, 4955, and 4958 . . . . . ▶ _____ 0		
d	Section 501(c)(3), 501(c)(4), and 501(c)(29) organizations. Enter amount of tax on line 40c reimbursed by the organization . . . . . ▶ _____ 0		
e	All organizations. At any time during the tax year, was the organization a party to a prohibited tax shelter transaction? If "Yes," complete Form 8886-T . . . . .		✓
40e			
41	List the states with which a copy of this return is filed ▶ CA, TX, VA, NY, OH,		
42a	The organization's books are in care of ▶ Phyllis Rogers Telephone no. ▶ 703 568 7989 Located at ▶ 101 Cottontail Drive Lake Frederick VA ZIP + 4 ▶ 22630		
b	At any time during the calendar year, did the organization have an interest in or a signature or other authority over a financial account in a foreign country (such as a bank account, securities account, or other financial account)? If "Yes," enter the name of the foreign country ▶ _____ See the instructions for exceptions and filing requirements for FinCEN Form 114, Report of Foreign Bank and Financial Accounts (FBAR).		✓
42b			
c	At any time during the calendar year, did the organization maintain an office outside the United States? If "Yes," enter the name of the foreign country ▶ _____		✓
42c			
43	Section 4947(a)(1) nonexempt charitable trusts filing Form 990-EZ in lieu of Form 1041 — Check here and enter the amount of tax-exempt interest received or accrued during the tax year . . . . . ▶ <u>43</u>		
44a	Did the organization maintain any donor advised funds during the year? If "Yes," Form 990 must be completed instead of Form 990-EZ . . . . .		✓
44a			
b	Did the organization operate one or more hospital facilities during the year? If "Yes," Form 990 must be completed instead of Form 990-EZ . . . . .		✓
44b			
c	Did the organization receive any payments for indoor tanning services during the year? . . . . .		✓
44c			
d	If "Yes" to line 44c, has the organization filed a Form 720 to report these payments? If "No," provide an explanation in Schedule O . . . . .		
44d			
45a	Did the organization have a controlled entity within the meaning of section 512(b)(13)? . . . . .		✓
b	Did the organization receive any payment from or engage in any transaction with a controlled entity within the meaning of section 512(b)(13)? If "Yes," Form 990 and Schedule R may need to be completed instead of Form 990-EZ. See instructions . . . . .		✓
45b			

46 Did the organization engage, directly or indirectly, in political campaign activities on behalf of or in opposition to candidates for public office? If "Yes," complete Schedule C, Part I . . . . .  Yes  No

**Part VI Section 501(c)(3) Organizations Only**

All section 501(c)(3) organizations must answer questions 47-49b and 52, and complete the tables for lines 50 and 51.

Check if the organization used Schedule O to respond to any question in this Part VI . . . . .

47 Did the organization engage in lobbying activities or have a section 501(h) election in effect during the tax year? If "Yes," complete Schedule C, Part II . . . . .  Yes  No

48 Is the organization a school as described in section 170(b)(1)(A)(ii)? If "Yes," complete Schedule E . . . . .  47  48

49a Did the organization make any transfers to an exempt non-charitable related organization? . . . . .  49a  49b

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

(a) Name and title of each employee	(b) Average hours per week devoted to position	(c) Reportable compensation (Forms W-2/1099-MISC)	(d) Health benefits, contributions to employee benefit plans, and deferred compensation	(e) Estimated amount of other compensation
NONE				

f Total number of other employees paid over \$100,000 . . . . . 0

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

(a) Name and business address of each independent contractor	(b) Type of service	(c) Compensation
NONE		

d Total number of other independent contractors each receiving over \$100,000 . . . . . 0

52 Did the organization complete Schedule A? Note: All section 501(c)(3) organizations must attach a completed Schedule A . . . . .  Yes  No

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: Leah Balent Date: 9/11/20  
Type or print name and title: Leah Balent

**Paid Preparer Use Only** Print/Type preparer's name: \_\_\_\_\_ Preparer's signature: \_\_\_\_\_ Date: \_\_\_\_\_  
Check  if self-employed PTIN: \_\_\_\_\_  
Firm's name: \_\_\_\_\_ Firm's EIN: \_\_\_\_\_  
Firm's address: \_\_\_\_\_ Phone no.: \_\_\_\_\_

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

**SCHEDULE A**  
**(Form 990 or 990-EZ)**

Department of the Treasury  
Internal Revenue Service

**Public Charity Status and Public Support**

Complete if the organization is a section 501(c)(3) organization or a section 4947(a)(1) nonexempt charitable trust.  
▶ Attach to Form 990 or Form 990-EZ.  
▶ Go to [www.irs.gov/Form990](http://www.irs.gov/Form990) for instructions and the latest information.

OMB No. 1545-0047

**2019**

**Open to Public Inspection**

Name of the organization  
**International Sacral Agenesis / Caudal Regression Association**

Employer identification number  
**45564733**

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

- The organization is not a private foundation because it is: (For lines 1 through 12, check only one box.)
- 1  A church, convention of churches, or association of churches described in **section 170(b)(1)(A)(i)**.
  - 2  A school described in **section 170(b)(1)(A)(ii)**. (Attach Schedule E (Form 990 or 990-EZ).)
  - 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 agricultural research organization described in **section 170(b)(1)(A)(ix)** operated in conjunction with a land-grant college or university or a non-land-grant college of agriculture (see instructions). Enter the name, city, and state of the college or university:
  - 10  An organization that normally receives: (1) more than 33 1/3% of its support from contributions, membership fees, and gross receipts from activities related to its exempt functions—subject to certain exceptions, and (2) no more than 33 1/3% of its support from gross investment income and unrelated business taxable income (less section 511 tax) from businesses acquired by the organization after June 30, 1975. See **section 509(a)(2)**. (Complete Part III.)
  - 11  An organization organized and operated exclusively to test for public safety. See **section 509(a)(4)**.
  - 12  An organization organized and operated exclusively for the benefit of, to perform the functions of, or to carry out the purposes of one or more publicly supported organizations described in **section 509(a)(1)** or **section 509(a)(2)**. See **section 509(a)(3)**. Check the box in lines 12a through 12d that describes the type of supporting organization and complete lines 12e, 12f, and 12g.
    - a  **Type I.** A supporting organization operated, supervised, or controlled by its supported organization(s), typically by giving the supported organization(s) the power to regularly appoint or elect a majority of the directors or trustees of the supporting organization. **You must complete Part IV, Sections A and B.**
    - b  **Type II.** A supporting organization supervised or controlled in connection with its supported organization(s), by having control or management of the supporting organization vested in the same persons that control or manage the supported organization(s). **You must complete Part IV, Sections A and C.**
    - c  **Type III functionally integrated.** A supporting organization operated in connection with, and functionally integrated with, its supported organization(s) (see instructions). **You must complete Part IV, Sections A, D, and E.**
    - d  **Type III non-functionally integrated.** A supporting organization operated in connection with its supported organization(s) that is not functionally integrated. The organization generally must satisfy a distribution requirement and an attentiveness requirement (see instructions). **You must complete Part IV, Sections A and D, and Part V.**
    - e  Check this box if the organization received a written determination from the IRS that it is a Type I, Type II, Type III functionally integrated, or Type III non-functionally integrated supporting organization.
    - f Enter the number of supported organizations . . . . .
    - g Provide the following information about the supported organization(s).

(i) Name of supported organization	(ii) EIN	(iii) Type of organization (described on lines 1–10 above (see instructions))	(iv) Is the organization listed in your governing document?		(v) Amount of monetary support (see instructions)	(vi) Amount of other support (see instructions)
			Yes	No		
(A)						
(B)						
(C)						
(D)						
(E)						
<b>Total</b>						

**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) 2015	(b) 2016	(c) 2017	(d) 2018	(e) 2019	(f) Total
<b>1</b> Gifts, grants, contributions, and membership fees received. (Do not include any "unusual grants.") . . . . .	6947	1473	3558	5588	6213	23779
<b>2</b> Tax revenues levied for the organization's benefit and either paid to or expended on its behalf . . . . .	0	0	0	0	0	0
<b>3</b> The value of services or facilities furnished by a governmental unit to the organization without charge . . . . .	0	0	0	0	0	0
<b>4 Total.</b> Add lines 1 through 3 . . . . .	6947	1473	3558	5588	6213	23779
<b>5</b> 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) . . . . .						
<b>6 Public support.</b> Subtract line 5 from line 4						

**Section B. Total Support**

Calendar year (or fiscal year beginning in) ▶	(a) 2015	(b) 2016	(c) 2017	(d) 2018	(e) 2019	(f) Total
<b>7</b> Amounts from line 4 . . . . .	6847	1473	3558	5588	6213	23779
<b>8</b> Gross income from interest, dividends, payments received on securities loans, rents, royalties, and income from similar sources . . . . .	0	0	0	0	0	0
<b>9</b> Net income from unrelated business activities, whether or not the business is regularly carried on . . . . .	0	0	0	0	0	0
<b>10</b> Other income. Do not include gain or loss from the sale of capital assets (Explain in Part VI.) . . . . .	0	0	0	0	0	0
<b>11 Total support.</b> Add lines 7 through 10						23779
<b>12</b> Gross receipts from related activities, etc. (see instructions) . . . . .					12	
<b>13 First five years.</b> 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 <b>stop here</b> . . . . . ▶ <input type="checkbox"/>						

**Section C. Computation of Public Support Percentage**

<b>14</b> Public support percentage for 2019 (line 6, column (f) divided by line 11, column (f)) . . . . .	<b>14</b>	100 %
<b>15</b> Public support percentage from 2018 Schedule A, Part II, line 14 . . . . .	<b>15</b>	100 %
<b>16a 33 1/3% support test—2019.</b> If the organization did not check the box on line 13, and line 14 is 33 1/3% or more, check this box and <b>stop here.</b> The organization qualifies as a publicly supported organization . . . . . ▶ <input checked="" type="checkbox"/>		
<b>b 33 1/3% support test—2018.</b> 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 <b>stop here.</b> The organization qualifies as a publicly supported organization . . . . . ▶ <input type="checkbox"/>		
<b>17a 10%-facts-and-circumstances test—2019.</b> 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 <b>stop here.</b> Explain in Part VI how the organization meets the "facts-and-circumstances" test. The organization qualifies as a publicly supported organization . . . . . ▶ <input type="checkbox"/>		
<b>b 10%-facts-and-circumstances test—2018.</b> 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 <b>stop here.</b> Explain in Part VI how the organization meets the "facts-and-circumstances" test. The organization qualifies as a publicly supported organization . . . . . ▶ <input type="checkbox"/>		
<b>18 Private foundation.</b> 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 O**  
**(Form 990 or 990-EZ)**

Department of the Treasury  
Internal Revenue Service

Name of the organization

International Sacral Agenesis/Caudal Regression Association (ISACRA)

**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.

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

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**2019**

Open to Public  
Inspection

Employer identification number

45-564733

"Other expenses"

support for attendance at conferences and events for and about those with rare disorders \$366.08

maintain informative and robust website and resources \$1386.66

Provided 3 college scholarships to universities for tuition for individuals with the condition of sacral agenesis/caudal regression syndrome  
\$2250.00

reimburse individuals/families postage expense for exchange of medical equipment \$59.98