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Form 990

Department of the Treasury
Internal Revenue Service

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)

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

OMB No 1545-0047

2011

Open to Public Inspection

A For the 2011 calendar year, or tax year beginning 01-01-2011 and ending 12-31-2011

B Check if applicable

☐ Address change

☐ Name change

☐ Initial return

☐ Terminated

☐ Amended return

☐ Application pending

C Name of organization

INTERNATIONAL FOUNDATION FOR CDKL5 RESEARCH

Doing Business As

Number and street (or P O box if mail is not delivered to street address)

P O BOX 926

Room/suite

City or town, state or country, and ZIP + 4

WADSWORTH, OH 44282

F Name and address of principal officer

KAREN UTLEY

325 BRAZOSWOOD

CLUTE, TX 77531

H(a) Is this a group return for affiliates?

☐ Yes ☒ No

H(b) Are all affiliates included?

☐ Yes ☐ No

If "No," attach a list (see instructions)

H(c) Group exemption number

I Tax-exempt status

☒ 501(c)(3) ☐ 501(c) () ☐ (Insert no) ☐ 4947(a)(1) or ☐ 527

J Website:

www.cdkl5.com

K Form of organization

☒ Corporation ☐ Trust ☐ Association ☐ Other

L Year of formation

2009

M State of legal domicile

OH

Part I

Summary

Activities & Governance	1 Briefly describe the organization's mission or most significant activities To fund research aimed at finding a cure for CDKL5, a rare genetic disorder		
	2 Check this box ☐ 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	7
	4 Number of independent voting members of the governing body (Part VI, line 1b)	4	7
	5 Total number of individuals employed in calendar year 2011 (Part V, line 2a)	5	0
	6 Total number of volunteers (estimate if necessary)	6	11
	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	
Revenue	8 Contributions and grants (Part VIII, line 1h)	Prior Year	Current Year
	9 Program service revenue (Part VIII, line 2g)		325,877
	10 Investment income (Part VIII, column (A), lines 3, 4, and 7d)		0
	11 Other revenue (Part VIII, column (A), lines 5, 6d, 8c, 9c, 10c, and 11e)		1,248
	12 Total revenue—add lines 8 through 11 (must equal Part VIII, column (A), line 12)		0
Expenses	13 Grants and similar amounts paid (Part IX, column (A), lines 1–3)		327,125
	14 Benefits paid to or for members (Part IX, column (A), line 4)		100,500
	15 Salaries, other compensation, employee benefits (Part IX, column (A), lines 5–10)		0
	16a Professional fundraising fees (Part IX, column (A), line 11e)		0
	16b Total fundraising expenses (Part IX, column (D), line 25) ☐ -753		
	17 Other expenses (Part IX, column (A), lines 11a–11d, 11f–24e)		0
	18 Total expenses Add lines 13–17 (must equal Part IX, column (A), line 25)		6,416
Net Assets or Fund Balances	19 Revenue less expenses Subtract line 18 from line 12		106,916
			220,209
		Beginning of Current Year	End of Year
	20 Total assets (Part X, line 16)	142,496	363,636
	21 Total liabilities (Part X, line 26)		0
	22 Net assets or fund balances Subtract line 21 from line 20	142,496	363,636

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

KAREN UTLEY TREASURER

2012-10-12

Date

Paid Preparer's Use Only

Preparer's signature

JUDY L ARFA CPA

Date

2012-10-11

Check if self-employed

☒

Preparer's taxpayer identification number (see instructions)

Firm's name (or yours if self-employed), address, and ZIP + 4

JUDY L ARFA CPA

4265 SAN FELIPE 1100

HOUSTON, TX 77027

EIN

Phone no

(713) 240-3315

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

☒ Yes ☐ No

For Paperwork Reduction Act Notice, see the separate instructions.

Cat No 11282Y

Form 990 (2011)

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

To fund research aimed at finding

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

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 and section 4947(a)(1) trusts 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 \$ 103,926 including grants of \$ 100,500) (Revenue \$)

A NUMBER OF FUNDRAISERS WERE HELD IN 2011 IN ADDITION, CONTRIBUTIONS WERE RECEIVED FROM NUMEROUS INDIVIDUALS, CORPORATIONS, AND FOUNDATIONS AS A RESULT, GRANTS TOTALING \$100,500 WERE MADE DURING 2011 TO FUND RESEARCH THAT WILL LEAD TO A CURE FOR THIS VERY DEBILITATING DISEASE IN THE NEAR FUTURE THE ORGANIZATION'S GOALS INCLUDE AGGRESSIVE RESEARCH, STUDIES TO IMPROVE THE QUALITY OF LIFE FOR CHILDREN WITH CDKL5, AND TESTING OF COMPOUNDS TO IDENTIFY NEUROLOGIC MODIFIERS

4b (Code) (Expenses \$ including grants of \$) (Revenue \$)

4c (Code) (Expenses \$ including grants of \$) (Revenue \$)

4d	Other program services (Describe in Schedule O)	(Expenses \$)	including grants of \$)	(Revenue \$)
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4e	Total program service expenses	\$ 103,926
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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	Yes
2	Is the organization required to complete <i>Schedule B, Schedule of Contributors</i> (see instructions)? 	2	Yes
3	Did the organization engage in direct or indirect political campaign activities on behalf of or in opposition to candidates for public office? <i>If "Yes," complete Schedule C, Part I.</i>	3	No
4	Section 501(c)(3) organizations. Did the organization engage in lobbying activities, or have a section 501(h) election in effect during the tax year? <i>If "Yes," complete Schedule C, Part II.</i>	4	No
5	Is the organization a section 501(c)(4), 501(c)(5), or 501(c)(6) organization that receives membership dues, assessments, or similar amounts as defined in Revenue Procedure 98-19? <i>If "Yes," complete Schedule C, Part III.</i>	5	No
6	Did the organization maintain any donor advised funds or any similar funds or accounts for which donors have the right to provide advice on the distribution or investment of amounts in such funds or accounts? <i>If "Yes," complete Schedule D, Part I.</i>	6	No
7	Did the organization receive or hold a conservation easement, including easements to preserve open space, the environment, historic land areas or historic structures? <i>If "Yes," complete Schedule D, Part II.</i>	7	No
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	No
9	Did the organization report an amount in Part X, line 21, 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	No
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	No
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	No
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	No
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	No
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	No
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	No
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	No
12a	Did the organization obtain separate, independent audited financial statements for the tax year? <i>If "Yes," complete Schedule D, Parts XI, XII, and XIII.</i> 	12a	Yes
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, XII, and XIII is optional.</i>	12b	No
13	Is the organization a school described in section 170(b)(1)(A)(ii)? <i>If "Yes," complete Schedule E.</i>	13	No
14a	Did the organization maintain an office, employees, or agents outside of the United States?	14a	No
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, Part I.</i>	14b	No
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 U S ? <i>If "Yes," complete Schedule F, Part II and IV.</i>	15	No
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 U S ? <i>If "Yes," complete Schedule F, Part III and IV.</i>	16	No
17	Did the organization report a total of more than \$15,000, of expenses for professional fundraising services on Part IX, column (A), lines 6 and 11e? <i>If "Yes," complete Schedule G, Part I.</i>	17	No
18	Did the organization report more than \$15,000 total of fundraising event gross income and contributions on Part VIII, lines 1c and 8a? <i>If "Yes," complete Schedule G, Part II.</i> 	18	Yes
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	No
20a	Did the organization operate one or more hospitals? <i>If "Yes," complete Schedule H.</i>	20a	No
b	If "Yes" to line 20a, did the organization attach its audited financial statement to this return? Note. All Form 990 filers that operated one or more hospitals must attach audited financial statements.	20b	

Part IV

Checklist of Required Schedules (continued)

21	Did the organization report more than \$5,000 of grants and other assistance to governments and organizations in the United States on Part IX, column (A), line 1? <i>If "Yes," complete Schedule I, Parts I and II</i>	21	Yes	
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>	22		No
23	Did the organization answer "Yes" to Part VII, Section A, questions 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>	23		No
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 questions 24b-24d and complete Schedule K. If "No," go to line 25</i>	24a		No
b	Did the organization invest any proceeds of tax-exempt bonds beyond a temporary period exception?	24b		
c	Did the organization maintain an escrow account other than a refunding escrow at any time during the year to defease any tax-exempt bonds?	24c		
d	Did the organization act as an "on behalf of" issuer for bonds outstanding at any time during the year?	24d		
25a	Section 501(c)(3) 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>	25a		No
b	Is the organization aware that it engaged in an excess benefit transaction with a disqualified person in a prior year, and that the transaction has not been reported on any of the organization's prior Forms 990 or 990-EZ? <i>If "Yes," complete Schedule L, Part I</i>	25b		No
26	Was a loan to or by a current or former officer, director, trustee, key employee, highly 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>	26		No
27	Did the organization provide a grant or other assistance to an officer, director, trustee, key employee, substantial contributor, or a grant selection committee member, or to a person related to such an individual? <i>If "Yes," complete Schedule L, Part III</i>	27		No
28	Was the organization a party to a business transaction with one of the following parties? (see Schedule L, Part IV instructions for applicable filing thresholds, conditions, and exceptions)			
a	A current or former officer, director, trustee, or key employee? <i>If "Yes," complete Schedule L, Part IV</i>	28a		No
b	A family member of a current or former officer, director, trustee, or key employee? <i>If "Yes," complete Schedule L, Part IV</i>	28b		No
c	An entity of which a current or former officer, director, trustee, or key employee (or a family member thereof) was an officer, director, trustee, or owner? <i>If "Yes," complete Schedule L, Part IV</i>	28c		No
29	Did the organization receive more than \$25,000 in non-cash contributions? <i>If "Yes," complete Schedule M</i>	29		No
30	Did the organization receive contributions of art, historical treasures, or other similar assets, or qualified conservation contributions? <i>If "Yes," complete Schedule M</i>	30		No
31	Did the organization liquidate, terminate, or dissolve and cease operations? <i>If "Yes," complete Schedule N, Part I</i>	31		No
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>	32		No
33	Did the organization own 100% of an entity disregarded as separate from the organization under Regulations sections 301.7701-2 and 301.7701-3? <i>If "Yes," complete Schedule R, Part I</i>	33		No
34	Was the organization related to any tax-exempt or taxable entity? <i>If "Yes," complete Schedule R, Parts II, III, IV, and V, line 1</i>	34		No
35a	Is any related organization a controlled entity of the filing organization within the meaning of section 512(b)(13)?	35a		No
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)? <i>If "Yes," complete Schedule R, Part V, line 2</i>	35b		No
36	Section 501(c)(3) organizations. Did the organization make any transfers to an exempt non-charitable related organization? <i>If "Yes," complete Schedule R, Part V, line 2</i>	36		
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>	37		No
38	Did the organization complete Schedule O and provide explanations in Schedule O for Part VI, lines 11 and 19? Note. All Form 990 filers are required to complete Schedule O	38	Yes	

Part V Statements Regarding Other IRS Filings and Tax Compliance			
Check 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. .	1a	0
b	Enter the number of Forms W-2G included in line 1a. Enter -0- if not applicable.	1b	0
c	Did the organization comply with backup withholding rules for reportable payments to vendors and reportable gaming (gambling) winnings to prize winners?	1c	Yes
2a	Enter the number of employees reported on Form W-3, <i>Transmittal of Wage and Tax Statements</i> filed for the calendar year ending with or within the year covered by this return.	2a	0
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).	2b	
3a	Did the organization have unrelated business gross income of \$1,000 or more during the year?	3a	No
b	If "Yes," has it filed a Form 990-T for this year? If "No," provide an explanation in Schedule O.	3b	
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 or securities account)?	4a	No
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?	5a	No
b	Did any taxable party notify the organization that it was or is a party to a prohibited tax shelter transaction?	5b	No
c	If "Yes" to line 5a or 5b, did the organization file Form 8886-T?	5c	
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?	6a	No
b	If "Yes," did the organization include with every solicitation an express statement that such contributions or gifts were not tax deductible?	6b	
7	Organizations that may receive deductible contributions under section 170(c).		
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?	7a	Yes
b	If "Yes," did the organization notify the donor of the value of the goods or services provided?	7b	Yes
c	Did the organization sell, exchange, or otherwise dispose of tangible personal property for which it was required to file Form 8282?	7c	No
d	If "Yes," indicate the number of Forms 8282 filed during the year.	7d	
e	Did the organization receive any funds, directly or indirectly, to pay premiums on a personal benefit contract?	7e	No
f	Did the organization, during the year, pay premiums, directly or indirectly, on a personal benefit contract?	7f	No
g	If the organization received a contribution of qualified intellectual property, did the organization file Form 8899 as required?	7g	
h	If the organization received a contribution of cars, boats, airplanes, or other vehicles, did the organization file a Form 1098-C?	7h	
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?	8	
9	Sponsoring organizations maintaining donor advised funds.		
a	Did the organization make any taxable distributions under section 4966?	9a	
b	Did the organization make a distribution to a donor, donor advisor, or related person?	9b	
10	Section 501(c)(7) organizations. Enter		
a	Initiation fees and capital contributions included on Part VIII, line 12.	10a	
b	Gross receipts, included on Form 990, Part VIII, line 12, for public use of club facilities.	10b	
11	Section 501(c)(12) organizations. Enter		
a	Gross income from members or shareholders.	11a	
b	Gross income from other sources (Do not net amounts due or paid to other sources against amounts due or received from them).	11b	
12a	Section 4947(a)(1) non-exempt charitable trusts. Is the organization filing Form 990 in lieu of Form 1041?	12a	
b	If "Yes," enter the amount of tax-exempt interest received or accrued during the year.	12b	
13	Section 501(c)(29) qualified nonprofit health insurance issuers.		
a	Is the organization licensed to issue qualified health plans in more than one state? Note. All 501(c)(29) organizations must list in Schedule O each state in which they are licensed to issue qualified health plans, the amount of reserves required by each state, and the amount of reserves the organization allocated to each state.	13a	
b	Enter the aggregate amount of reserves the organization is required to maintain by the states in which the organization is licensed to issue qualified health plans.	13b	
c	Enter the aggregate amount of reserves on hand.	13c	
14a	Did the organization receive any payments for indoor tanning services during the tax year?	14a	No
b	If "Yes," has it filed a Form 720 to report these payments? If "No," provide an explanation in Schedule O.	14b	

Part VI

Governance, Management, and Disclosure

For each "Yes" response to lines 2 through 7b below, and for a "No" response to lines 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

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

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?		No
10b	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?	Yes	
11b	Describe in Schedule O the process, if any, used by the organization to review the Form 990		
12a	Did the organization have a written conflict of interest policy? If "No," go to line 13	Yes	
12b	Were officers, directors or trustees, and key employees required to disclose annually interests that could give rise to conflicts?	Yes	
12c	Did the organization regularly and consistently monitor and enforce compliance with the policy? If "Yes," describe in Schedule O how this was done	Yes	
13	Did the organization have a written whistleblower policy?		No
14	Did the organization have a written document retention and destruction policy?		No
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?		
15a	The organization's CEO, Executive Director, or top management official		No
15b	Other officers or key employees of the organization		No
	If "Yes," to line 15a or 15b, describe the process in Schedule O (see instructions)		
16a	Did the organization invest in, contribute assets to, or participate in a joint venture or similar arrangement with a taxable entity during the year?		No
16b	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	CT , MI , OH
18	Section 6104 requires an organization to make its Form 1023 (or 1024 if applicable), 990, and 990-T (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	
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. See Additional Data Table.	
20	State the name, physical address, and telephone number of the person who possesses the books and records of the organization.	KAREN UTLEY BOX 984325 BRAZOSWOOD CLUTE, TX 77531 (979) 265-3411

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

☒ Check this box if neither the organization nor any related organizations compensated any current or former officer, director, or trustee

Form **990** (2011)

Part VII

1b	Sub-Total	▼			
c	Total from continuation sheets to Part VII, Section A	▼			
d	Total (add lines 1b and 1c)	▼			

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: 0

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

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

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 Revenue

				(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	1a	Federated campaigns . . .	1a 273,255				
	b	Membership dues	1b 860				
	c	Fundraising events	1c 51,762				
	d	Related organizations	1d				
	e	Government grants (contributions)	1e				
	f	All other contributions, gifts, grants, and similar amounts not included above	1f				
	g	Noncash contributions included in lines 1a-1f \$ _____					
	h	Total. Add lines 1a-1f					
Program Service Revenue	2a	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)		1,650		
4		Income from investment of tax-exempt bond proceeds . .					
5		Royalties					
6a		Gross rents	(i) Real (ii) Personal				
b		Less rental expenses					
c		Rental income or (loss)					
d		Net rental income or (loss)					
7a		Gross amount from sales of assets other than inventory	(i) Securities (ii) Other				
b		Less cost or other basis and sales expenses	5,467 5,869				
c		Gain or (loss)	-402				
d		Net gain or (loss)					
8a		Gross income from fundraising events (not including \$ 51,762 of contributions reported on line 1c) See Part IV, line 18	a 9,009				
b		Less direct expenses	b 9,009				
c		Net income or (loss) from fundraising events . .					
9a		Gross income from gaming activities See Part IV, line 19	a				
b		Less direct expenses	b				
c		Net income or (loss) from gaming activities . .					
10a		Gross sales of inventory, less returns and allowances	a				
b		Less cost of goods sold	b				
c		Net income or (loss) from sales of inventory . .					
Miscellaneous Revenue		Business Code					
11a							
b							
c							
d	All other revenue						
e	Total. Add lines 11a-11d						
12	Total revenue. See Instructions		327,125	-402		1,650	

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) but are not required to complete columns (B), (C), and (D)

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

Do not include amounts reported on lines 6b, 7b, 8b, 9b, and 10b of Part VIII.		(A) Total expenses	(B) Program service expenses	(C) Management and general expenses	(D) Fundraising expenses
1	Grants and other assistance to governments and organizations in the United States See Part IV, line 21	100,500	100,500		
2	Grants and other assistance to individuals in the United States See Part IV, line 22				
3	Grants and other assistance to governments, organizations, and individuals outside the United States See Part IV, lines 15 and 16				
4	Benefits paid to or for members				
5	Compensation of current officers, directors, trustees, and key employees				
6	Compensation not included above, to disqualified persons (as defined under section 4958(f)(1)) and persons described in section 4958(c)(3)(B)				
7	Other salaries and wages				
8	Pension plan contributions (include section 401(k) and section 403(b) employer contributions)				
9	Other employee benefits				
10	Payroll taxes				
11	Fees for services (non-employees)				
a	Management				
b	Legal				
c	Accounting	900	0	900	0
d	Lobbying				
e	Professional fundraising See Part IV, line 17				
f	Investment management fees				
g	Other				
12	Advertising and promotion				
13	Office expenses	123	123	0	0
14	Information technology				
15	Royalties				
16	Occupancy				
17	Travel				
18	Payments of travel or entertainment expenses for any federal, state, or local public officials				
19	Conferences, conventions, and meetings	1,000	1,000	0	0
20	Interest				
21	Payments to affiliates				
22	Depreciation, depletion, and amortization				
23	Insurance	1,885	943	189	753
24	Other expenses Itemize expenses not covered above (List miscellaneous expenses in line 24f If line 24f amount exceeds 10% of line 25, column (A) amount, list line 24f expenses on Schedule O)				
a	Business Expenses	42	0	42	0
b	Business Registration	345	0	345	0
c	Bank Charges	761	0	761	0
d	Postage	414	414	0	0
e					
f	All other expenses	946	946	0	0
25	Total functional expenses. Add lines 1 through 24f	106,916	103,926	2,237	753
26	Joint costs. Check here ☐ if following SOP 98-2 (ASC 958-720) Complete this line only if the organization reported in column (B) joint costs from a combined educational campaign and fundraising solicitation				

Part X

Balance Sheet

					(A)		(B)
					Beginning of year		End of year
Assets	1	Cash—non-interest-bearing			142,496	1	332,784
	2	Savings and temporary cash investments				2	
	3	Pledges and grants receivable, net				3	25,000
	4	Accounts receivable, net				4	
	5	Receivables from current and former officers, directors, trustees, key employees, and highest compensated employees Complete Part II of Schedule L				5	
	6	Receivables from other disqualified persons (as defined under section 4958(f)(1)) and persons described in section 4958(c)(3)(B) Complete Part II of Schedule L				6	
	7	Notes and loans receivable, net				7	
	8	Inventories for sale or use				8	
	9	Prepaid expenses and deferred charges				9	
	10a	Land, buildings, and equipment cost or other basis Complete Part VI of Schedule D	10a			10c	
	b	Less accumulated depreciation	10b				
	11	Investments—publicly traded securities				11	5,852
	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				15	
	16	Total assets. Add lines 1 through 15 (must equal line 34)			142,496	16	363,636
Liabilities	17	Accounts payable and accrued expenses				17	
	18	Grants payable				18	
	19	Deferred revenue				19	
	20	Tax-exempt bond liabilities				20	
	21	Escrow or custodial account liability Complete Part IV of Schedule D				21	
	22	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				25	
	26	Total liabilities. Add lines 17 through 25			0	26	0
Net Assets or Fund Balances	Organizations that follow SFAS 117, check here ☒ and complete lines 27 through 29, and lines 33 and 34.						
	27	Unrestricted net assets			142,496	27	318,636
	28	Temporarily restricted net assets				28	45,000
	29	Permanently restricted net assets				29	
	Organizations that do not follow SFAS 117, check here ☐ 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			142,496	33	363,636
	34	Total liabilities and net assets/fund balances			142,496	34	363,636

Part XI Reconciliation of Net Assets

Check 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	327,125
2	Total expenses (must equal Part IX, column (A), line 25)	2	106,916
3	Revenue less expenses Subtract line 2 from line 1	3	220,209
4	Net assets or fund balances at beginning of year (must equal Part X, line 33, column (A))	4	142,496
5	Other changes in net assets or fund balances (explain in Schedule O)	5	931
6	Net assets or fund balances at end of year Combine lines 3, 4, and 5 (must equal Part X, line 33, column (B))	6	363,636

Part XII Financial Statements and Reporting

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

		Yes	No
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?		No
b	Were the organization's financial statements audited by an independent accountant?	Yes	
c	If "Yes," to 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	Yes	
d	If "Yes" to line 2a or 2b, check a box below to indicate whether the financial statements for the year were issued on a separate basis, consolidated basis, or both ☒ Separate basis ☐ Consolidated basis ☐ Both consolidated and separated basis		
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?		No
b	If "Yes," did the organization undergo the required audit or audits? If the organization did not undergo the required audit or audits, explain why in Schedule O and describe any steps taken to undergo such audits		

SCHEDULE A
(Form 990 or 990EZ)

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

2011

Open to Public Inspection

Name of the organization
INTERNATIONAL FOUNDATION FOR CDKL5 RESEARCH

Employer identification number
27-0950477

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 **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)(vi)** (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 Se**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 - Other

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 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 support?
			Yes	No	Yes	No	Yes	No	
Total									

Part II

Support Schedule for Organizations Described in IRC 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) 2007	(b) 2008	(c) 2009	(d) 2010	(e) 2011	(f) Total
1 Gifts, grants, contributions, and membership fees received (Do not include any "unusual grants ")				144,605	325,877	470,482
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				144,605	325,877	470,482
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)						139,441
6 Public Support. Subtract line 5 from line 4						331,041

Section B. Total Support							
Calendar year (or fiscal year beginning in)		(a) 2007	(b) 2008	(c) 2009	(d) 2010	(e) 2011	(f) Total
7	Amounts from line 4				144,605	325,877	470,482
8	Gross income from interest, dividends, payments received on securities loans, rents, royalties and income from similar sources				316	1,650	1,966
9	Net income from unrelated business activities, whether or not the business is regularly carried on						
10	Other income (Explain in Part IV) Do not include gain or loss from the sale of capital assets					-402	-402
11	Total support (Add lines 7 through 10)						472,046
12	Gross receipts from related activities, etc (See instructions)					12	5,467
13	First Five Years If the Form 990 is for the organization's first, second, third, fourth, or fifth tax year as a 501(c)(3) organization, check this box and stop here						☒

Section C. Computation of Public Support Percentage			
14	Public Support Percentage for 2011 (line 6 column (f) divided by line 11 column (f))	14	0 %
15	Public Support Percentage for 2010 Schedule A, Part II, line 14	15	
16a	33 1/3% support test—2011. 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		
b	33 1/3% support test—2010. If the organization did not check the box on line 13 or 16a, and line 15 is 33 1/3% or more, check this box and stop here. The organization qualifies as a publicly supported organization		
17a	10%-facts-and-circumstances test—2011. 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		
b	10%-facts-and-circumstances test—2010. 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		
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		

Part IIIPart III

Support Schedule for Organizations Described in IRC 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) 2007	(b) 2008	(c) 2009	(d) 2010	(e) 2011	(f) Total
1 Gifts, grants, contributions, and membership fees received (Do not include any "unusual grants.")						
2 Gross receipts from admissions, merchandise sold or services performed, or facilities furnished in any activity that is related to the organization's tax-exempt purpose						
3 Gross receipts from activities that are not an unrelated trade or business under section 513						
4 Tax revenues levied for the organization's benefit and either paid to or expended on its behalf						
5 The value of services or facilities furnished by a governmental unit to the organization without charge						
6 Total. Add lines 1 through 5						
7a Amounts included on lines 1, 2, and 3 received from disqualified persons						
b Amounts included on lines 2 and 3 received from other than disqualified persons that exceed the greater of \$5,000 or 1% of the amount on line 13 for the year						
c Add lines 7a and 7b						
8 Public Support (Subtract line 7c from line 6.)						0

Section B. Total Support						
Calendar year (or fiscal year beginning in)	(a) 2007	(b) 2008	(c) 2009	(d) 2010	(e) 2011	(f) Total
9 Amounts from line 6						
10a Gross income from interest, dividends, payments received on securities loans, rents, royalties and income from similar sources						
b Unrelated business taxable income (less section 511 taxes) from businesses acquired after June 30, 1975						
c Add lines 10a and 10b						
11 Net income from unrelated business activities not included 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.)						
14 First Five Years If the Form 990 is for the organization's first, second, third, fourth, or fifth tax year as a 501(c)(3) organization, check this box and stop here						☐

Section C. Computation of Public Support Percentage		
15 Public Support Percentage for 2011 (line 8 column (f) divided by line 13 column (f))	15	0 %
16 Public support percentage from 2010 Schedule A, Part III, line 15	16	

Section D. Computation of Investment Income Percentage		
17 Investment income percentage for 2011 (line 10c column (f) divided by line 13 column (f))	17	0 %
18 Investment income percentage from 2010 Schedule A, Part III, line 17	18	
19a 33 1/3% support tests—2011. 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—2010. 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		☐

Part IV **Supplemental Information.** Supplemental Information. Complete this part to provide the explanation required by Part II, line 10; Part II, line 17a or 17b; or Part III, line 12. Also complete this part for any additional information. (See instructions).

Facts And Circumstances Test

Explanation

Additional Data

Software ID: 11000175
Software Version:
EIN: 27-0950477
Name: INTERNATIONAL FOUNDATION FOR CDKL5 RESEARCH

Form 990, Special Condition Description:

Special Condition Description

SCHEDULE D
(Form 990)

Department of the Treasury
Internal Revenue Service

Supplemental Financial Statements

OMB No 1545-0047

2011

Open to Public Inspection

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

▶ Attach to Form 990. ▶ See separate instructions.

Name of the organization
INTERNATIONAL FOUNDATION FOR CDKL5 RESEARCH

Employer identification number
27-0950477

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?	
	☐ Yes ☐ No	
6	Did the organization inform all grantees, donors, and donor advisors in writing that grant funds may 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	
	☐ Yes ☐ 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)

☐ Preservation of land for public use (e g , recreation or pleasure)

☐ Preservation of an historically importantly land area

☐ Protection of natural habitat

☐ Preservation of a certified historic structure

☐ Preservation of open space

2

Complete lines 2a–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 Year
a	Total number of conservation easements
b	Total acreage restricted by conservation easements
c	Number of conservation easements on a certified historic structure included in (a)
d	Number of conservation easements included in (c) acquired after 8/17/06

3

Number of conservation easements modified, transferred, released, extinguished, or terminated by the organization during the taxable 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 170(h)(4)(B)(ii)?

☐ Yes ☐ No

9

In Part XIV, 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, 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 XIV, the text of the footnote to its financial statements that describes these items

b

If the organization elected, as permitted under SFAS 116, 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 relating to these items

a

Revenues included in Form 990, Part VIII, line 1

▶ \$ _____

b

Assets included in Form 990, Part X

▶ \$ _____

For Privacy Act and Paperwork Reduction Act Notice, see the Intructions for Form 990

Cat No 52283D

Schedule D (Form 990) 2011

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

3 Using the organization’s 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
- d** ☐ Loan or exchange programs
- b** ☐ Scholarly research
- e** ☐ Other
- c** ☐ Preservation for future generations

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

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 XIV and complete the following table

	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 XIV

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 Investment earnings or 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 year end balance held as

- a** Board designated or quasi-endowment ▶
- b** Permanent endowment ▶
- c** Term endowment ▶

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

	Yes	No
(i) unrelated organizations	3a(i)	
(ii) related organizations	3a(ii)	
b If "Yes" to 3a(ii), are the related organizations listed as required on Schedule R?	3b	

4 Describe in Part XIV 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				
e Other				
Total. Add lines 1a-1e <i>(Column (d) should equal Form 990, Part X, column (B), line 10(c).)</i> ▶				

Part XI Reconciliation of Change in Net Assets from Form 990 to Financial Statements			
1	Total revenue (Form 990, Part VIII, column (A), line 12)	1	327,125
2	Total expenses (Form 990, Part IX, column (A), line 25)	2	106,916
3	Excess or (deficit) for the year Subtract line 2 from line 1	3	220,209
4	Net unrealized gains (losses) on investments	4	829
5	Donated services and use of facilities	5	
6	Investment expenses	6	
7	Prior period adjustments	7	
8	Other (Describe in Part XIV)	8	
9	Total adjustments (net) Add lines 4 - 8	9	829
10	Excess or (deficit) for the year per financial statements Combine lines 3 and 9	10	221,038

Part XII Reconciliation of Revenue per Audited Financial Statements With Revenue per Return			
1	Total revenue, gains, and other support per audited financial statements	1	336,963
2	Amounts included on line 1 but not on Form 990, Part VIII, line 12		
a	Net unrealized gains on investments	2a	829
b	Donated services and use of facilities	2b	
c	Recoveries of prior year grants	2c	
d	Other (Describe in Part XIV)	2d	
e	Add lines 2a through 2d	2e	829
3	Subtract line 2e from line 1	3	336,134
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 XIV)	4b	-9,009
c	Add lines 4a and 4b	4c	-9,009
5	Total Revenue Add lines 3 and 4c. (This should equal Form 990, Part I, line 12)	5	327,125

Part XIII Reconciliation of Expenses per Audited Financial Statements With Expenses per Return			
1	Total expenses and losses per audited financial statements	1	115,925
2	Amounts included on line 1 but not on Form 990, Part IX, line 25		
a	Donated services and use of facilities	2a	
b	Prior year adjustments	2b	
c	Other losses	2c	
d	Other (Describe in Part XIV)	2d	9,009
e	Add lines 2a through 2d	2e	9,009
3	Subtract line 2e from line 1	3	106,916
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 XIV)	4b	
c	Add lines 4a and 4b	4c	
5	Total expenses Add lines 3 and 4c. (This should equal Form 990, Part I, line 18)	5	106,916

Part XIV 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, Part XI, line 8, Part XII, lines 2d and 4b, and Part XIII, lines 2d and 4b Also complete this part to provide any additional information

Identifier	Return Reference	Explanation
Pt XII Line 4b		Fundraising Expenses 9,009
Pt XIII Line 2d		Fundraising Expenses 9,009

SCHEDULE G
(Form 990 or 990-EZ)

Department of the Treasury
Internal Revenue Service

Supplemental Information Regarding
Fundraising or Gaming Activities

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.

OMB No 1545-0047

2011

Open to Public
Inspection

Name of the organization
INTERNATIONAL FOUNDATION FOR CDKL5 RESEARCH

Employer identification number
27-0950477

Part I Fundraising Activities. Complete if the organization answered "Yes" to Form 990, Part IV, line 17.

1

Indicate whether the organization raised funds through any of the following activities. Check all that apply.

a

☐ Mail solicitations

b

☐ Internet and e-mail solicitations

c

☐ Phone solicitations

d

☐ In-person solicitations

e

☐ Solicitation of non-government grants

f

☐ Solicitation of government grants

g

☐ Special fundraising events

2a

Did the organization have a written or oral agreement with any individual (including officers, directors, trustees or key employees listed in Form 990, Part VII) or entity in connection with professional fundraising services?

☐ Yes ☐ No

b

If "Yes," list the ten highest paid individuals or entities (fundraisers) pursuant to agreements under which the fundraiser is to be compensated at least \$5,000 by the organization. Form 990-EZ filers are not required to complete this table.

(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			
Total ▶						

3

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

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

Cat No 50083H

Schedule G (Form 990 or 990-EZ) 2011

Part II Fundraising Events. Complete if the organization answered "Yes" to Form 990, Part IV, line 18, or reported more than \$15,000 on Form 990-EZ, line 6a. List events with gross receipts greater than \$5,000.

		(a) Event #1	(b) Event #2	(c) Other Events	(d) Total Events
		MI Walk (event type)	TX Scramble (event type)	(total number)	(Add col (a) through col (c))
Revenue	1	Gross receipts	25,588	7,670	27,513
	2	Less Charitable contributions	20,833	6,295	24,634
	3	Gross income (line 1 minus line 2)	4,755	1,375	2,879
Direct Expenses	4	Cash prizes			
	5	Non-cash prizes	4,755	1,375	2,879
	6	Rent/facility costs			
	7	Food and beverages			
	8	Entertainment			
	9	Other direct expenses			
	10	Direct expense summary Add lines 4 through 9 in column (d) ▶			
	11	Net income summary Combine lines 3 and 10 in column (d). ▶			

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))
Revenue	1	Gross revenue			
	2	Cash prizes			
Direct Expenses	3	Non-cash prizes			
	4	Rent/facility costs			
	5	Other direct expenses			
	6	Volunteer labor	☐ Yes ☐ No	☐ Yes ☐ No	
	7	Direct expense summary Add lines 2 through 5 in column (d) ▶			
	8	Net gaming income summary Combine lines 1 and 7 in column (d) ▶			

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	13a
b	An outside facility	13b

- 14
- Provide 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

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 distributed to other exempt organizations or spent in the organization's own exempt activities during the tax year \$

Part IV

Complete this part to provide additional information for responses to question on Schedule G (see instructions.)

Identifier	ReturnReference	Explanation
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Schedule I
(Form 990)

Department of the Treasury
Internal Revenue Service

Name of the organization
INTERNATIONAL FOUNDATION FOR CDKL5 RESEARCH

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

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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. Check this box if no one recipient received more than \$5,000. Use Part IV and Schedule I-1 (Form 990) if additional space is needed ☐

(a) Name and address of organization or government	(b) EIN	(c) IRC Code 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
(1) TRUSTEES UNIVERSITY OF PA3451 WALNUT STREET PHILADELPHIA,PA 19104	23-1352685		33,000		N/A	N/A	Research
(2) REGENTS UNIV OF CA 1111 FRANKLIN ST OAKLAND,CA 94607	94-3067788		50,000		N/A	N/A	Research
(3) INT'L RETT SYNDROME 4600 DEVITT DRIVE CINCINATTI,OH 45246	31-1682518	501(c)(3)	17,500		N/A	N/A	Research

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

3 Enter total number of other organizations listed in the line 1 table 0

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.
Use Schedule I-1 (Form 990) 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

Part IV

Supplemental Information. Complete this part to provide the information required in Part I, line 2, and any other additional information.

Identifier	Return Reference	Explanation
Pt I Line 2		A group of Board members monitor how these funds are being used on a
		monthly basis. Reports are provided to the Organization by the grantee
		organizations that give updates on research activities

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 to provide any additional information.
▶ Attach to Form 990 or 990-EZ.

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Name of the organization INTERNATIONAL FOUNDATION FOR CDKL5 RESEARCH	Employer identification number 27-0950477
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Identifier	Return Reference	Explanation
Pt VI, Line 11a		The form is reviewed by the Board Treasurer and other
		members of the Board. All questions are reviewed to make
		certain that there are no incorrect answers.
Pt VI, Line 19		Upon request, they are provided to grantors, contributors,
		and Board members.
Pt XI		Changes In Net Assets
		Prior Period Adjustment At 1/1/11 - 102
		Unrealized gain on securities held at 12/31/11 - 829
		TOTAL 931
Pt XII, Line 1		Reason for change in accounting method - The Organization
		is now having an annual audit. They are required to be
		on the accrual basis beginning in 2011.
Pt VI, Line 4		Amended by-laws were enacted during 2011. The number and
		terms of the members of the Board of Directors were
		changed, and a provision was added regarding how a
		deadlock should be managed if Board members cannot reach a
		decision about important Organization matters.
Pt VI, Line 6		The Organization has members that pay a fee and are
		entitled to serve on special advisory Boards and
		committees.

Identifier	Return Reference	Explanation
Pt VI, Line 12c		Questionnaires are required to be completed by all
		Board members annually Should there be reasons for
		concern, there is a detailed review of all
		transactions that appear to be a cause for concern
Form 990EZ, Part I, Line 16		BANK FEES FEDERAL FEES ACCOUNTING FEES STATE REGISTRATION FEES OFFICE EXPENSE
Form 990, Part IX, Line 24f		PRINTING 17 17 0 0 TELEPHONE 21 21 0 0 VOLUNTEER EXPENSES 171 171 0 0 PROFESSIONAL FEES 485 485 0 0 OPERATIONS 252 252 0 0