

**JUDY L. ARFA, CPA PLLC**  
**4265 SAN FELIPE #1100**  
**HOUSTON, TX 77027**  
**(713) 240-3315**  
**[judy@arfacpa.com](mailto:judy@arfacpa.com)**

October 23, 2024

International Foundation For CDKL5 Research  
P O Box 926  
Wadsworth, OH 44282

Dear Ms. Utley,

Enclosed is the 2023 U.S. Form 990, Return of Organization Exempt from Income Tax, for International Foundation For CDKL5 Research for the tax year ending December 31, 2023.

Your 2023 U.S. Form 990, Return of Organization Exempt from Income Tax, return will be electronically filed.

We very much appreciate the opportunity to serve you. If you have any questions regarding this return, please do not hesitate to call.

Sincerely,

A handwritten signature in black ink that reads "Judy L. Arfa, CPA". The signature is written in a cursive style.

Judy L Arfa, CPA

Return of Organization Exempt From Income Tax

2023

Department of the Treasury Internal Revenue Service

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

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

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

Open to Public Inspection

Header section A-M containing organization details, tax-exempt status, and website information.

Part I Summary

Table with 22 rows detailing financial and operational data, including mission statement, revenue, expenses, and net assets.

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.

Signature area for Karen Utley, President, dated 10/20/2024.

Paid Preparer Use Only section for Judy L Arfa, CPA, dated 10/23/2024.

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

**Part III Statement of Program Service Accomplishments**

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

**1** Briefly describe the organization's mission:  
To fund research aimed at finding a cure for CDKL5, a rare genetic disorder.  
A family conference is funded by the Organization every two years  
to provide support to families whose loved ones suffer from CDKL5.

**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 \$ 403,158. including grants of \$ 197,884.) (Revenue \$ 0.)  
A number of fundraisers were held in 2023. In addition, contributions were received from numerous individuals, corporations, and foundations. As a result, grants totaling \$197,884 were made during 2023 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 on Schedule O.)  
(Expenses \$ including grants of \$ ) (Revenue \$ )

**4e** Total program service expenses 403,158.

**Part IV Checklist of Required Schedules**

	Yes	No
<b>1</b> 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>	<b>1</b> X	
<b>2</b> Is the organization required to complete Schedule B, Schedule of Contributors? See instructions . . . . .	<b>2</b> X	
<b>3</b> Did the organization engage in direct or indirect political campaign activities on behalf of or in opposition to candidates for public office? <i>If "Yes," complete Schedule C, Part I . . . . .</i>		X
<b>4</b> <b>Section 501(c)(3) organizations.</b> Did the organization engage in lobbying activities, or have a section 501(h) election in effect during the tax year? <i>If "Yes," complete Schedule C, Part II . . . . .</i>		X
<b>5</b> Is the organization a section 501(c)(4), 501(c)(5), or 501(c)(6) organization that receives membership dues, assessments, or similar amounts as defined in Rev. Proc. 98-19? <i>If "Yes," complete Schedule C, Part III . . . . .</i>		X
<b>6</b> Did the organization maintain any donor advised funds or any similar funds or accounts for which donors have the right to provide advice on the distribution or investment of amounts in such funds or accounts? <i>If "Yes," complete Schedule D, Part I . . . . .</i>		X
<b>7</b> Did the organization receive or hold a conservation easement, including easements to preserve open space, the environment, historic land areas, or historic structures? <i>If "Yes," complete Schedule D, Part II . . . . .</i>		X
<b>8</b> Did the organization maintain collections of works of art, historical treasures, or other similar assets? <i>If "Yes," complete Schedule D, Part III . . . . .</i>		X
<b>9</b> Did the organization report an amount in Part X, line 21, for escrow or custodial account liability; serve as a custodian for amounts not listed in Part X; or provide credit counseling, debt management, credit repair, or debt negotiation services? <i>If "Yes," complete Schedule D, Part IV . . . . .</i>		X
<b>10</b> Did the organization, directly or through a related organization, hold assets in donor-restricted endowments or in quasi-endowments? <i>If "Yes," complete Schedule D, Part V . . . . .</i>		X
<b>11</b> 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.		
<b>a</b> 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>	<b>11a</b>	X
<b>b</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>	<b>11b</b>	X
<b>c</b> 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>	<b>11c</b>	X
<b>d</b> 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>	<b>11d</b>	X
<b>e</b> Did the organization report an amount for other liabilities in Part X, line 25? <i>If "Yes," complete Schedule D, Part X . . . . .</i>	<b>11e</b>	X
<b>f</b> 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>	<b>11f</b>	X
<b>12a</b> Did the organization obtain separate, independent audited financial statements for the tax year? <i>If "Yes," complete Schedule D, Parts XI and XII . . . . .</i>	<b>12a</b>	X
<b>b</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>	<b>12b</b>	X
<b>13</b> Is the organization a school described in section 170(b)(1)(A)(ii)? <i>If "Yes," complete Schedule E . . . . .</i>	<b>13</b>	X
<b>14a</b> Did the organization maintain an office, employees, or agents outside of the United States? . . . . .	<b>14a</b>	X
<b>b</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>	<b>14b</b>	X
<b>15</b> Did the organization report on Part IX, column (A), line 3, more than \$5,000 of grants or other assistance to or for any foreign organization? <i>If "Yes," complete Schedule F, Parts II and IV . . . . .</i>	<b>15</b>	X
<b>16</b> Did the organization report on Part IX, column (A), line 3, more than \$5,000 of aggregate grants or other assistance to or for foreign individuals? <i>If "Yes," complete Schedule F, Parts III and IV . . . . .</i>	<b>16</b>	X
<b>17</b> 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. See instructions . . . . .</i>	<b>17</b>	X
<b>18</b> 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>	<b>18</b> X	
<b>19</b> 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>	<b>19</b>	X
<b>20a</b> Did the organization operate one or more hospital facilities? <i>If "Yes," complete Schedule H . . . . .</i>	<b>20a</b>	X
<b>b</b> If "Yes" to line 20a, did the organization attach a copy of its audited financial statements to this return? . . . . .	<b>20b</b>	
<b>21</b> Did the organization report more than \$5,000 of grants or other assistance to any domestic organization or domestic government on Part IX, column (A), line 1? <i>If "Yes," complete Schedule I, Parts I and II . . . . .</i>	<b>21</b> X	

**Part IV Checklist of Required Schedules** *(continued)*

		Yes	No
<b>22</b>	Did the organization report more than \$5,000 of grants or other assistance to or for domestic individuals on Part IX, column (A), line 2? <i>If "Yes," complete Schedule I, Parts I and III</i>		X
<b>23</b>	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
<b>24a</b>	Did the organization have a tax-exempt bond issue with an outstanding principal amount of more than \$100,000 as of the last day of the year, that was issued after December 31, 2002? <i>If "Yes," answer lines 24b through 24d and complete Schedule K. If "No," go to line 25a</i>		X
<b>b</b>	Did the organization invest any proceeds of tax-exempt bonds beyond a temporary period exception?		
<b>c</b>	Did the organization maintain an escrow account other than a refunding escrow at any time during the year to defease any tax-exempt bonds?		
<b>d</b>	Did the organization act as an "on behalf of" issuer for bonds outstanding at any time during the year?		
<b>25a</b>	<b>Section 501(c)(3), 501(c)(4), and 501(c)(29) organizations.</b> Did the organization engage in an excess benefit transaction with a disqualified person during the year? <i>If "Yes," complete Schedule L, Part I</i>		X
<b>b</b>	Is the organization aware that it engaged in an excess benefit transaction with a disqualified person in a prior year, and that the transaction has not been reported on any of the organization's prior Forms 990 or 990-EZ? <i>If "Yes," complete Schedule L, Part I</i>		X
<b>26</b>	Did the organization report any amount on Part X, line 5 or 22, for receivables from or payables to any current or former officer, director, trustee, key employee, creator or founder, substantial contributor, or 35% controlled entity or family member of any of these persons? <i>If "Yes," complete Schedule L, Part II</i>		X
<b>27</b>	Did the organization provide a grant or other assistance to any current or former officer, director, trustee, key employee, creator or founder, substantial contributor or employee thereof, a grant selection committee member, or to a 35% controlled entity (including an employee thereof) or family member of any of these persons? <i>If "Yes," complete Schedule L, Part III</i>		X
<b>28</b>	Was the organization a party to a business transaction with one of the following parties? (See the Schedule L, Part IV, instructions for applicable filing thresholds, conditions, and exceptions).		
<b>a</b>	A current or former officer, director, trustee, key employee, creator or founder, or substantial contributor? <i>If "Yes," complete Schedule L, Part IV</i>		X
<b>b</b>	A family member of any individual described in line 28a? <i>If "Yes," complete Schedule L, Part IV</i>		X
<b>c</b>	A 35% controlled entity of one or more individuals and/or organizations described in line 28a or 28b? <i>If "Yes," complete Schedule L, Part IV</i>		X
<b>29</b>	Did the organization receive more than \$25,000 in noncash contributions? <i>If "Yes," complete Schedule M</i>	X	
<b>30</b>	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
<b>31</b>	Did the organization liquidate, terminate, or dissolve and cease operations? <i>If "Yes," complete Schedule N, Part I</i>		X
<b>32</b>	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
<b>33</b>	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
<b>34</b>	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
<b>35a</b>	Did the organization have a controlled entity within the meaning of section 512(b)(13)?		X
<b>b</b>	If "Yes" to line 35a, did the organization receive any payment from or engage in any transaction with a controlled entity within the meaning of section 512(b)(13)? <i>If "Yes," complete Schedule R, Part V, line 2</i>		X
<b>36</b>	<b>Section 501(c)(3) organizations.</b> 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
<b>37</b>	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
<b>38</b>	Did the organization complete Schedule O and provide explanations on Schedule O for Part VI, lines 11b and 19? <b>Note:</b> All Form 990 filers are required to complete Schedule O	X	

**Part V Statements Regarding Other IRS Filings and Tax Compliance**

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

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

<b>Part V Statements Regarding Other IRS Filings and Tax Compliance</b> <i>(continued)</i>		Yes	No		
<b>2a</b>	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>2a</b>	0		
<b>b</b>	If at least one is reported on line 2a, did the organization file all required federal employment tax returns?	<b>2b</b>			
<b>3a</b>	Did the organization have unrelated business gross income of \$1,000 or more during the year?	<b>3a</b>			X
<b>b</b>	If "Yes," has it filed a Form 990-T for this year? <i>If "No" to line 3b, provide an explanation on Schedule O</i>	<b>3b</b>			
<b>4a</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)?	<b>4a</b>			X
<b>b</b>	If "Yes," enter the name of the foreign country _____ See instructions for filing requirements for FinCEN Form 114, Report of Foreign Bank and Financial Accounts (FBAR).				
<b>5a</b>	Was the organization a party to a prohibited tax shelter transaction at any time during the tax year?	<b>5a</b>			X
<b>b</b>	Did any taxable party notify the organization that it was or is a party to a prohibited tax shelter transaction?	<b>5b</b>			X
<b>c</b>	If "Yes" to line 5a or 5b, did the organization file Form 8886-T?	<b>5c</b>			
<b>6a</b>	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?	<b>6a</b>			X
<b>b</b>	If "Yes," did the organization include with every solicitation an express statement that such contributions or gifts were not tax deductible?	<b>6b</b>			
<b>7</b>	<b>Organizations that may receive deductible contributions under section 170(c).</b>				
<b>a</b>	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?	<b>7a</b>			X
<b>b</b>	If "Yes," did the organization notify the donor of the value of the goods or services provided?	<b>7b</b>			
<b>c</b>	Did the organization sell, exchange, or otherwise dispose of tangible personal property for which it was required to file Form 8282?	<b>7c</b>			X
<b>d</b>	If "Yes," indicate the number of Forms 8282 filed during the year	<b>7d</b>			
<b>e</b>	Did the organization receive any funds, directly or indirectly, to pay premiums on a personal benefit contract?	<b>7e</b>			X
<b>f</b>	Did the organization, during the year, pay premiums, directly or indirectly, on a personal benefit contract?	<b>7f</b>			X
<b>g</b>	If the organization received a contribution of qualified intellectual property, did the organization file Form 8899 as required?	<b>7g</b>			
<b>h</b>	If the organization received a contribution of cars, boats, airplanes, or other vehicles, did the organization file a Form 1098-C?	<b>7h</b>			
<b>8</b>	<b>Sponsoring organizations maintaining donor advised funds.</b> Did a donor advised fund maintained by the sponsoring organization have excess business holdings at any time during the year?	<b>8</b>			
<b>9</b>	<b>Sponsoring organizations maintaining donor advised funds.</b>				
<b>a</b>	Did the sponsoring organization make any taxable distributions under section 4966?	<b>9a</b>			
<b>b</b>	Did the sponsoring organization make a distribution to a donor, donor advisor, or related person?	<b>9b</b>			
<b>10</b>	<b>Section 501(c)(7) organizations.</b> Enter:				
<b>a</b>	Initiation fees and capital contributions included on Part VIII, line 12	<b>10a</b>			
<b>b</b>	Gross receipts, included on Form 990, Part VIII, line 12, for public use of club facilities	<b>10b</b>			
<b>11</b>	<b>Section 501(c)(12) organizations.</b> Enter:				
<b>a</b>	Gross income from members or shareholders	<b>11a</b>			
<b>b</b>	Gross income from other sources. (Do not net amounts due or paid to other sources against amounts due or received from them.)	<b>11b</b>			
<b>12a</b>	<b>Section 4947(a)(1) non-exempt charitable trusts.</b> Is the organization filing Form 990 in lieu of Form 1041?	<b>12a</b>			
<b>b</b>	If "Yes," enter the amount of tax-exempt interest received or accrued during the year	<b>12b</b>			
<b>13</b>	<b>Section 501(c)(29) qualified nonprofit health insurance issuers.</b>				
<b>a</b>	Is the organization licensed to issue qualified health plans in more than one state? <b>Note:</b> See the instructions for additional information the organization must report on Schedule O.	<b>13a</b>			
<b>b</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	<b>13b</b>			
<b>c</b>	Enter the amount of reserves on hand	<b>13c</b>			
<b>14a</b>	Did the organization receive any payments for indoor tanning services during the tax year?	<b>14a</b>			X
<b>b</b>	If "Yes," has it filed a Form 720 to report these payments? <i>If "No," provide an explanation on Schedule O</i>	<b>14b</b>			
<b>15</b>	Is the organization subject to the section 4960 tax on payment(s) of more than \$1,000,000 in remuneration or excess parachute payment(s) during the year? If "Yes," see the instructions and file Form 4720, Schedule N.	<b>15</b>			X
<b>16</b>	Is the organization an educational institution subject to the section 4968 excise tax on net investment income? If "Yes," complete Form 4720, Schedule O.	<b>16</b>			X
<b>17</b>	<b>Section 501(c)(21) organizations.</b> Did the trust, or any disqualified or other person, engage in any activities that would result in the imposition of an excise tax under section 4951, 4952, or 4953? If "Yes," complete Form 6069.	<b>17</b>			

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

**Section A. Governing Body and Management**

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

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

		Yes	No
<b>10a</b>	Did the organization have local chapters, branches, or affiliates? . . . . .		X
<b>b</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? . . . . .		
<b>10b</b>			
<b>11a</b>	Has the organization provided a complete copy of this Form 990 to all members of its governing body before filing the form? . . . . .	X	
<b>b</b>	Describe on Schedule O the process, if any, used by the organization to review this Form 990. . . . .		
<b>12a</b>	Did the organization have a written conflict of interest policy? If "No," go to line 13 . . . . .	X	
<b>b</b>	Were officers, directors, or trustees, and key employees required to disclose annually interests that could give rise to conflicts? . . . . .	X	
<b>c</b>	Did the organization regularly and consistently monitor and enforce compliance with the policy? If "Yes," describe on Schedule O how this was done . . . . .	X	
<b>12c</b>		X	
<b>13</b>	Did the organization have a written whistleblower policy? . . . . .	X	
<b>14</b>	Did the organization have a written document retention and destruction policy? . . . . .	X	
<b>15</b>	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?		
<b>a</b>	The organization's CEO, Executive Director, or top management official . . . . .		X
<b>b</b>	Other officers or key employees of the organization . . . . .		X
	If "Yes" to line 15a or 15b, describe the process on Schedule O. See instructions. . . . .		
<b>16a</b>	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>b</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? . . . . .		
<b>16b</b>			

**Section C. Disclosure**

- 17** List the states with which a copy of this Form 990 is required to be filed \_\_\_\_\_
- 18** Section 6104 requires an organization to make its Forms 1023 (1024 or 1024-A, if applicable), 990, and 990-T (section 501(c)(3)s only) available for public inspection. Indicate how you made these available. Check all that apply.  
 Own website     Another's website     Upon request     Other (explain on Schedule O)
- 19** Describe on Schedule O whether (and if so, how) the organization made its governing documents, conflict of interest policy, and financial statements available to the public during the tax year.
- 20** State the name, address, and telephone number of the person who possesses the organization's books and records.  
 Karen Utley, 325 Brazoswood, Clute, TX 77531 (979) 265-3411

**Part VII Compensation of Officers, Directors, Trustees, Key Employees, Highest Compensated Employees, and Independent Contractors**

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

**Section A. Officers, Directors, Trustees, Key Employees, and Highest Compensated Employees**

**1a** Complete this table for all persons required to be listed. Report compensation for the calendar year ending with or within the organization's tax year.

- List all of the organization's **current** officers, directors, trustees (whether individuals or organizations), regardless of amount of compensation. Enter -0- in columns (D), (E), and (F) if no compensation was paid.
- List all of the organization's **current** key employees, if any. See the instructions for definition of "key employee."
- List the organization's five **current** highest compensated employees (other than an officer, director, trustee, or key employee) who received reportable compensation (box 5 of Form W-2, box 6 of Form 1099-MISC, and/or box 1 of Form 1099-NEC) of more than \$100,000 from the organization and any related organizations.
- List all of the organization's **former** officers, key employees, and highest compensated employees who received more than \$100,000 of reportable compensation from the organization and any related organizations.
- List all of the organization's **former directors or trustees** that received, in the capacity as a former director or trustee of the organization, more than \$10,000 of reportable compensation from the organization and any related organizations.

See the instructions for the order in which to list the persons above.

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

(A) Name and title	(B) Average hours per week (list any hours for related organizations below dotted line)	(C) Position (do not check more than one box, unless person is both an officer and a director/trustee)						(D) Reportable compensation from the organization (W-2/1099-MISC/1099-NEC)	(E) Reportable compensation from related organizations (W-2/1099-MISC/1099-NEC)	(F) Estimated amount of other compensation from the organization and related organizations
		Individual trustee or director	Institutional trustee	Officer	Key employee	Highest compensated employee	Former			
(1) Karen Utley President	35.00	X		X						
(2) Rick Upp Vice President	15.00	X		X						
(3) Paul Miller Secretary	15.00	X		X						
(4) Amanda Jaksha Treasurer	15.00	X		X						
(5) Miriam Blase Director	1.00	X								
(6) Garrett Decker Director	1.00	X								
(7) Marissa Bishop Director	1.00	X								
(8) Melissa Ralston Board Member Emeritus	1.00	X								
(9)										
(10)										
(11)										
(12)										
(13)										
(14)										

**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 dotted line)	(C) Position (do not check more than one box, unless person is both an officer and a director/trustee)						(D) Reportable compensation from the organization (W-2/1099-MISC/1099-NEC)	(E) Reportable compensation from related organizations (W-2/1099-MISC/1099-NEC)	(F) Estimated amount of other compensation from the organization and related organizations
		Individual trustee or director	Institutional trustee	Officer	Key employee	Highest compensated employee	Former			
(15)										
(16)										
(17)										
(18)										
(19)										
(20)										
(21)										
(22)										
(23)										
(24)										
(25)										
<b>1b Subtotal</b>										
<b>c Total from continuation sheets to Part VII, Section A</b>										
<b>d Total (add lines 1b and 1c)</b>										

**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
<b>3</b> Did the organization list any <b>former</b> officer, director, trustee, key employee, or highest compensated employee on line 1a? <i>If "Yes," complete Schedule J for such individual</i>	3	X
<b>4</b> 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	X
<b>5</b> 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	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

**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**

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

			(A) Total revenue	(B) Related or exempt function revenue	(C) Unrelated business revenue	(D) Revenue excluded from tax under sections 512-514	
<b>Contributions, Gifts, Grants, and Other Similar Amounts</b>	<b>1a</b>	Federated campaigns . . . . .	<b>1a</b>				
	<b>b</b>	Membership dues . . . . .	<b>1b</b>				
	<b>c</b>	Fundraising events . . . . .	<b>1c</b>	56,529.			
	<b>d</b>	Related organizations . . . . .	<b>1d</b>				
	<b>e</b>	Government grants (contributions)	<b>1e</b>				
	<b>f</b>	All other contributions, gifts, grants, and similar amounts not included above	<b>1f</b>	574,259.			
	<b>g</b>	Noncash contributions included in lines 1a-1f . . . . .	<b>1g</b>	\$ 42,217.			
	<b>h</b>	<b>Total.</b> Add lines 1a-1f . . . . .		630,788.			
	<b>Program Service Revenue</b>	<b>2a</b>	Business Code				
<b>b</b>							
<b>c</b>							
<b>d</b>							
<b>e</b>							
<b>f</b>		All other program service revenue . .					
<b>g</b>		<b>Total.</b> Add lines 2a-2f . . . . .					
<b>Other Revenue</b>	<b>3</b>	Investment income (including dividends, interest, and other similar amounts) . . . . .		3,044.	0.	0.	3,044.
	<b>4</b>	Income from investment of tax-exempt bond proceeds					
	<b>5</b>	Royalties . . . . .					
	<b>6a</b>	Gross rents . . . . .	(i) Real				
			(ii) Personal				
	<b>b</b>	Less: rental expenses	<b>6b</b>				
	<b>c</b>	Rental income or (loss)	<b>6c</b>				
	<b>d</b>	Net rental income or (loss) . . . . .					
	<b>7a</b>	Gross amount from sales of assets other than inventory	(i) Securities				
			(ii) Other				
	<b>b</b>	Less: cost or other basis and sales expenses . . . . .	<b>7b</b>				
	<b>c</b>	Gain or (loss) . . . . .	<b>7c</b>				
	<b>d</b>	Net gain or (loss) . . . . .					
	<b>8a</b>	Gross income from fundraising events (not including \$ 56,529. of contributions reported on line 1c). See Part IV, line 18 . . . . .	<b>8a</b>	1,238.			
<b>b</b>	Less: direct expenses . . . . .	<b>8b</b>	1,238.				
<b>c</b>	Net income or (loss) from fundraising events . . . . .		0.		0.	0.	
<b>9a</b>	Gross income from gaming activities. See Part IV, line 19 . . . . .						
<b>b</b>	Less: direct expenses . . . . .	<b>9b</b>					
<b>c</b>	Net income or (loss) from gaming activities . . . . .						
<b>10a</b>	Gross sales of inventory, less returns and allowances . . . . .						
<b>b</b>	Less: cost of goods sold . . . . .	<b>10b</b>					
<b>c</b>	Net income or (loss) from sales of inventory . . . . .						
<b>Miscellaneous Revenue</b>	<b>11a</b>	Business Code					
	<b>b</b>						
	<b>c</b>						
	<b>d</b>	All other revenue . . . . .		5,350.	0.	0.	5,350.
	<b>e</b>	<b>Total.</b> Add lines 11a-11d . . . . .		5,350.			
<b>12</b>	<b>Total revenue.</b> See instructions . . . . .		639,182.	0.	0.	8,394.	

**Part IX Statement of Functional Expenses**

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

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

**Do not include amounts reported on lines 6b, 7b, 8b, 9b, and 10b of Part VIII.**

	(A) Total expenses	(B) Program service expenses	(C) Management and general expenses	(D) Fundraising expenses
<b>1</b> Grants and other assistance to domestic organizations and domestic governments. See Part IV, line 21 . . . . .	197,884.	197,884.		
<b>2</b> Grants and other assistance to domestic individuals. See Part IV, line 22 . . . . .				
<b>3</b> Grants and other assistance to foreign organizations, foreign governments, and foreign individuals. See Part IV, lines 15 and 16				
<b>4</b> Benefits paid to or for members . . . . .				
<b>5</b> Compensation of current officers, directors, trustees, and key employees . . . . .				
<b>6</b> Compensation not included above to disqualified persons (as defined under section 4958(f)(1)) and persons described in section 4958(c)(3)(B) . . . . .				
<b>7</b> Other salaries and wages . . . . .				
<b>8</b> Pension plan accruals and contributions (include section 401(k) and 403(b) employer contributions)				
<b>9</b> Other employee benefits . . . . .				
<b>10</b> Payroll taxes . . . . .				
<b>11</b> Fees for services (nonemployees):				
<b>a</b> Management . . . . .				
<b>b</b> Legal . . . . .				
<b>c</b> Accounting . . . . .	1,250.	1,250.	0.	0.
<b>d</b> Lobbying . . . . .				
<b>e</b> Professional fundraising services. See Part IV, line 17				
<b>f</b> Investment management fees . . . . .				
<b>g</b> Other. (If line 11g amount exceeds 10% of line 25, column (A), amount, list line 11g expenses on Schedule O.) . . . . .	141,348.	141,348.	0.	0.
<b>12</b> Advertising and promotion . . . . .	1,082.	1,082.	0.	0.
<b>13</b> Office expenses . . . . .	858.	858.	0.	0.
<b>14</b> Information technology . . . . .				
<b>15</b> Royalties . . . . .				
<b>16</b> Occupancy . . . . .				
<b>17</b> Travel . . . . .	1,780.	1,780.	0.	0.
<b>18</b> Payments of travel or entertainment expenses for any federal, state, or local public officials				
<b>19</b> Conferences, conventions, and meetings . . . . .				
<b>20</b> Interest . . . . .				
<b>21</b> Payments to affiliates . . . . .				
<b>22</b> Depreciation, depletion, and amortization . . . . .	3,667.	3,667.	0.	0.
<b>23</b> Insurance . . . . .	2,864.	1,690.	344.	830.
<b>24</b> Other expenses. Itemize expenses not covered above. (List miscellaneous expenses on line 24e. If line 24e amount exceeds 10% of line 25, column (A), amount, list line 24e expenses on Schedule O.)				
<b>a</b> Fees - Payment Processing	3,963.	3,963.	0.	0.
<b>b</b> Business Registration	2,221.	2,221.	0.	0.
<b>c</b> Bank Charges	326.	0.	326.	0.
<b>d</b> Postage	2,892.	2,892.	0.	0.
<b>e</b> All other expenses	54,463.	44,523.	954.	8,986.
<b>25</b> <b>Total functional expenses.</b> Add lines 1 through 24e	414,598.	403,158.	1,624.	9,816.
<b>26</b> <b>Joint costs.</b> Complete this line only if the organization reported in column (B) joint costs from a combined educational campaign and fundraising solicitation. Check here <input type="checkbox"/> if following SOP 98-2 (ASC 958-720) . . . . .				

**Part X Balance Sheet**

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

		(A) Beginning of year		(B) End of year
<b>Assets</b>	<b>1</b> Cash—non-interest-bearing . . . . .	219,758.	<b>1</b>	284,614.
	<b>2</b> Savings and temporary cash investments . . . . .	296,248.	<b>2</b>	289,364.
	<b>3</b> Pledges and grants receivable, net . . . . .		<b>3</b>	
	<b>4</b> Accounts receivable, net . . . . .		<b>4</b>	
	<b>5</b> Loans and other receivables from any current or former officer, director, trustee, key employee, creator or founder, substantial contributor, or 35% controlled entity or family member of any of these persons . . . . .		<b>5</b>	
	<b>6</b> Loans and other receivables from other disqualified persons (as defined under section 4958(f)(1)), and persons described in section 4958(c)(3)(B) . . . . .		<b>6</b>	
	<b>7</b> Notes and loans receivable, net . . . . .		<b>7</b>	
	<b>8</b> Inventories for sale or use . . . . .		<b>8</b>	
	<b>9</b> Prepaid expenses and deferred charges . . . . .	13,399.	<b>9</b>	3,399.
	<b>10a</b> Land, buildings, and equipment: cost or other basis. Complete Part VI of Schedule D . . . . .	<b>10a</b>		
	<b>b</b> Less: accumulated depreciation . . . . .	<b>10b</b>		<b>10c</b>
	<b>11</b> Investments—publicly traded securities . . . . .	101,641.	<b>11</b>	165,432.
	<b>12</b> Investments—other securities. See Part IV, line 11 . . . . .		<b>12</b>	
	<b>13</b> Investments—program-related. See Part IV, line 11 . . . . .		<b>13</b>	
	<b>14</b> Intangible assets . . . . .		<b>14</b>	18,333.
	<b>15</b> Other assets. See Part IV, line 11 . . . . .		<b>15</b>	
<b>16 Total assets.</b> Add lines 1 through 15 (must equal line 33) . . . . .	631,046.	<b>16</b>	761,142.	
<b>Liabilities</b>	<b>17</b> Accounts payable and accrued expenses . . . . .	17,717.	<b>17</b>	1,432.
	<b>18</b> Grants payable . . . . .	294,540.	<b>18</b>	194,759.
	<b>19</b> Deferred revenue . . . . .		<b>19</b>	
	<b>20</b> Tax-exempt bond liabilities . . . . .		<b>20</b>	
	<b>21</b> Escrow or custodial account liability. Complete Part IV of Schedule D . . . . .		<b>21</b>	
	<b>22</b> Loans and other payables to any current or former officer, director, trustee, key employee, creator or founder, substantial contributor, or 35% controlled entity or family member of any of these persons . . . . .		<b>22</b>	
	<b>23</b> Secured mortgages and notes payable to unrelated third parties . . . . .		<b>23</b>	
	<b>24</b> Unsecured notes and loans payable to unrelated third parties . . . . .		<b>24</b>	
	<b>25</b> 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 . . . . .		<b>25</b>	
	<b>26 Total liabilities.</b> Add lines 17 through 25 . . . . .	312,257.	<b>26</b>	196,191.
<b>Net Assets or Fund Balances</b>	<b>Organizations that follow FASB ASC 958, check here <input checked="" type="checkbox"/> and complete lines 27, 28, 32, and 33.</b>			
	<b>27</b> Net assets without donor restrictions . . . . .	318,789.	<b>27</b>	564,951.
	<b>28</b> Net assets with donor restrictions . . . . .		<b>28</b>	
	<b>Organizations that do not follow FASB ASC 958, check here <input type="checkbox"/> and complete lines 29 through 33.</b>			
	<b>29</b> Capital stock or trust principal, or current funds . . . . .		<b>29</b>	
	<b>30</b> Paid-in or capital surplus, or land, building, or equipment fund . . . . .		<b>30</b>	
	<b>31</b> Retained earnings, endowment, accumulated income, or other funds . . . . .		<b>31</b>	
<b>32</b> Total net assets or fund balances . . . . .	318,789.	<b>32</b>	564,951.	
<b>33</b> Total liabilities and net assets/fund balances . . . . .	631,046.	<b>33</b>	761,142.	

**Part XI Reconciliation of Net Assets**

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

<b>1</b>	Total revenue (must equal Part VIII, column (A), line 12)	<b>1</b>	639,182.
<b>2</b>	Total expenses (must equal Part IX, column (A), line 25)	<b>2</b>	414,598.
<b>3</b>	Revenue less expenses. Subtract line 2 from line 1	<b>3</b>	224,584.
<b>4</b>	Net assets or fund balances at beginning of year (must equal Part X, line 32, column (A))	<b>4</b>	318,789.
<b>5</b>	Net unrealized gains (losses) on investments	<b>5</b>	21,036.
<b>6</b>	Donated services and use of facilities	<b>6</b>	
<b>7</b>	Investment expenses	<b>7</b>	
<b>8</b>	Prior period adjustments	<b>8</b>	542.
<b>9</b>	Other changes in net assets or fund balances (explain on Schedule O)	<b>9</b>	
<b>10</b>	Net assets or fund balances at end of year. Combine lines 3 through 9 (must equal Part X, line 32, column (B))	<b>10</b>	564,951.

**Part XII Financial Statements and Reporting**

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

	Yes	No
<b>1</b> Accounting method used to prepare the Form 990: <input type="checkbox"/> Cash <input checked="" type="checkbox"/> Accrual <input type="checkbox"/> Other _____ If the organization changed its method of accounting from a prior year or checked "Other," explain on Schedule O.		
<b>2a</b> Were the organization's financial statements compiled or reviewed by an independent accountant? If "Yes," check a box below to indicate whether the financial statements for the year were compiled or reviewed on a separate basis, consolidated basis, or both. <input type="checkbox"/> Separate basis <input type="checkbox"/> Consolidated basis <input type="checkbox"/> Both consolidated and separate basis		X
<b>b</b> Were the organization's financial statements audited by an independent accountant? If "Yes," check a box below to indicate whether the financial statements for the year were audited on a separate basis, consolidated basis, or both. <input type="checkbox"/> Separate basis <input type="checkbox"/> Consolidated basis <input type="checkbox"/> Both consolidated and separate basis		X
<b>c</b> If "Yes" to line 2a or 2b, does the organization have a committee that assumes responsibility for oversight of the audit, review, or compilation of its financial statements and selection of an independent accountant? If the organization changed either its oversight process or selection process during the tax year, explain on Schedule O.		
<b>3a</b> As a result of a federal award, was the organization required to undergo an audit or audits as set forth in the Uniform Guidance, 2 C.F.R. Part 200, Subpart F?		X
<b>b</b> If "Yes," did the organization undergo the required audit or audits? If the organization did not undergo the required audit or audits, explain why on Schedule O and describe any steps taken to undergo such audits.		

**SCHEDULE A  
(Form 990)**

Department of the Treasury  
Internal Revenue Service

**Public Charity Status and Public Support**

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

Attach to Form 990 or Form 990-EZ.

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

OMB No. 1545-0047

**2023**

**Open to Public  
Inspection**

<b>Name of the organization</b> International Foundation For CDKL5 Research	<b>Employer identification number</b> 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 12, check only one box.)

- 1  A church, convention of churches, or association of churches described in **section 170(b)(1)(A)(i)**.
- 2  A school described in **section 170(b)(1)(A)(ii)**. (Attach Schedule E (Form 990).)
- 3  A hospital or a cooperative hospital service organization described in **section 170(b)(1)(A)(iii)**.
- 4  A medical research organization operated in conjunction with a hospital described in **section 170(b)(1)(A)(iii)**. Enter the hospital's name, city, and state: \_\_\_\_\_
- 5  An organization operated for the benefit of a college or university owned or operated by a governmental unit described in **section 170(b)(1)(A)(iv)**. (Complete Part II.)
- 6  A federal, state, or local government or governmental unit described in **section 170(b)(1)(A)(v)**.
- 7  An organization that normally receives a substantial part of its support from a governmental unit or from the general public described in **section 170(b)(1)(A)(vi)**. (Complete Part II.)
- 8  A community trust described in **section 170(b)(1)(A)(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<sup>1</sup>/<sub>3</sub>% 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<sup>1</sup>/<sub>3</sub>% of its support from gross investment income and unrelated business taxable income (less section 511 tax) from businesses acquired by the organization after June 30, 1975. See **section 509(a)(2)**. (Complete Part III.)
- 11  An organization organized and operated exclusively to test for public safety. See **section 509(a)(4)**.
- 12  An organization organized and operated exclusively for the benefit of, to perform the functions of, or to carry out the purposes of one or more publicly supported organizations described in **section 509(a)(1)** or **section 509(a)(2)**. See **section 509(a)(3)**. Check the box on lines 12a through 12d that describes the type of supporting organization and complete lines 12e, 12f, and 12g.
  - a  **Type I.** A supporting organization operated, supervised, or controlled by its supported organization(s), typically by giving the supported organization(s) the power to regularly appoint or elect a majority of the directors or trustees of the supporting organization. **You must complete Part IV, Sections A and B.**
  - b  **Type II.** A supporting organization supervised or controlled in connection with its supported organization(s), by having control or management of the supporting organization vested in the same persons that control or manage the supported organization(s). **You must complete Part IV, Sections A and C.**
  - c  **Type III functionally integrated.** A supporting organization operated in connection with, and functionally integrated with, its supported organization(s) (see instructions). **You must complete Part IV, Sections A, D, and E.**
  - d  **Type III non-functionally integrated.** A supporting organization operated in connection with its supported organization(s) that is not functionally integrated. The organization generally must satisfy a distribution requirement and an attentiveness requirement (see instructions). **You must complete Part IV, Sections A and D, and Part V.**
  - e  Check this box if the organization received a written determination from the IRS that it is a Type I, Type II, Type III functionally integrated, or Type III non-functionally integrated supporting organization.
- f Enter the number of supported organizations
- g Provide the following information about the supported organization(s).

(i) Name of supported organization	(ii) EIN	(iii) Type of organization (described on lines 1-10 above (see instructions))	(iv) Is the organization listed in your governing document?		(v) Amount of monetary support (see instructions)	(vi) Amount of other support (see instructions)
			Yes	No		
(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) 2019	(b) 2020	(c) 2021	(d) 2022	(e) 2023	(f) Total
<b>1</b> Gifts, grants, contributions, and membership fees received. (Do not include any "unusual grants.") . . . . .	434,402.	505,914.	668,072.	606,015.	630,788.	2,845,191.
<b>2</b> Tax revenues levied for the organization's benefit and either paid to or expended on its behalf . . . . .						
<b>3</b> The value of services or facilities furnished by a governmental unit to the organization without charge . . . . .						
<b>4 Total.</b> Add lines 1 through 3 . . . . .	434,402.	505,914.	668,072.	606,015.	630,788.	2,845,191.
<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) . . . . .						473,755.
<b>6 Public support.</b> Subtract line 5 from line 4						2,371,436.

**Section B. Total Support**

Calendar year (or fiscal year beginning in)	(a) 2019	(b) 2020	(c) 2021	(d) 2022	(e) 2023	(f) Total
<b>7</b> Amounts from line 4 . . . . .	434,402.	505,914.	668,072.	606,015.	630,788.	2,845,191.
<b>8</b> Gross income from interest, dividends, payments received on securities loans, rents, royalties, and income from similar sources . . . . .	4,488.	931.	13.	574.	3,044.	9,050.
<b>9</b> Net income from unrelated business activities, whether or not the business is regularly carried on . . . . .						
<b>10</b> Other income. Do not include gain or loss from the sale of capital assets (Explain in Part VI.) . . . . .	23,654.	128,489.	9,962.		5,350.	167,455.
<b>11 Total support.</b> Add lines 7 through 10						3,021,696.
<b>12</b> Gross receipts from related activities, etc. (see instructions) . . . . .					<b>12</b> 95,000.	
<b>13 First 5 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 2023 (line 6, column (f), divided by line 11, column (f)) . . . . .	<b>14</b>	78.48 %
<b>15</b> Public support percentage from 2022 Schedule A, Part II, line 14 . . . . .	<b>15</b>	75.27 %
<b>16a 33 1/3% support test—2023.</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—2022.</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—2023.</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—2022.</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"/>

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

(Complete only if you checked the box on line 10 of Part I or if the organization failed to qualify under Part II. If the organization fails to qualify under the tests listed below, please complete Part II.)

**Section A. Public Support**

Calendar year (or fiscal year beginning in)	(a) 2019	(b) 2020	(c) 2021	(d) 2022	(e) 2023	(f) Total
<b>1</b> Gifts, grants, contributions, and membership fees received. (Do not include any "unusual grants.")						
<b>2</b> 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 . . . .						
<b>3</b> Gross receipts from activities that are not an unrelated trade or business under section 513						
<b>4</b> Tax revenues levied for the organization's benefit and either paid to or expended on its behalf . . . .						
<b>5</b> The value of services or facilities furnished by a governmental unit to the organization without charge . . . .						
<b>6 Total.</b> Add lines 1 through 5 . . . .						
<b>7a</b> Amounts included on lines 1, 2, and 3 received from disqualified persons . . . .						
<b>b</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						
<b>c</b> Add lines 7a and 7b . . . .						
<b>8 Public support.</b> (Subtract line 7c from line 6.) . . . .						

**Section B. Total Support**

Calendar year (or fiscal year beginning in)	(a) 2019	(b) 2020	(c) 2021	(d) 2022	(e) 2023	(f) Total
<b>9</b> Amounts from line 6 . . . .						
<b>10a</b> Gross income from interest, dividends, payments received on securities loans, rents, royalties, and income from similar sources						
<b>b</b> Unrelated business taxable income (less section 511 taxes) from businesses acquired after June 30, 1975 . . . .						
<b>c</b> Add lines 10a and 10b . . . .						
<b>11</b> Net income from unrelated business activities not included on line 10b, whether or not the business is regularly carried on						
<b>12</b> Other income. Do not include gain or loss from the sale of capital assets (Explain in Part VI.) . . . .						
<b>13 Total support.</b> (Add lines 9, 10c, 11, and 12.) . . . .						

**14 First 5 years.** If the Form 990 is for the organization's first, second, third, fourth, or fifth tax year as a section 501(c)(3) organization, check this box and **stop here** . . . .

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

<b>15</b> Public support percentage for 2023 (line 8, column (f), divided by line 13, column (f)) . . . .	<b>15</b>	%
<b>16</b> Public support percentage from 2022 Schedule A, Part III, line 15 . . . .	<b>16</b>	%

**Section D. Computation of Investment Income Percentage**

<b>17</b> Investment income percentage for <b>2023</b> (line 10c, column (f), divided by line 13, column (f)) . . . .	<b>17</b>	%
<b>18</b> Investment income percentage from <b>2022</b> Schedule A, Part III, line 17 . . . .	<b>18</b>	%

**19a 33 1/3% support tests—2023.** 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—2022.** 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 Supporting Organizations**

(Complete only if you checked a box on line 12 of Part I. If you checked box 12a, Part I, complete Sections A and B. If you checked box 12b, Part I, complete Sections A and C. If you checked box 12c, Part I, complete Sections A, D, and E. If you checked box 12d, Part I, complete Sections A and D, and complete Part V.)

**Section A. All Supporting Organizations**

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

**Part IV Supporting Organizations** (continued)

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

**Section B. Type I Supporting Organizations**

	Yes	No
<b>1</b> Did the governing body, members of the governing body, officers acting in their official capacity, or membership of one or more supported organizations have the power to regularly appoint or elect at least a majority of the organization's officers, directors, or trustees at all times during the tax year? If "No," describe in <b>Part VI</b> how the supported organization(s) effectively operated, supervised, or controlled the organization's activities. If the organization had more than one supported organization, describe how the powers to appoint and/or remove officers, directors, or trustees were allocated among the supported organizations and what conditions or restrictions, if any, applied to such powers during the tax year.		
<b>1</b>		
<b>2</b> Did the organization operate for the benefit of any supported organization other than the supported organization(s) that operated, supervised, or controlled the supporting organization? If "Yes," explain in <b>Part VI</b> how providing such benefit carried out the purposes of the supported organization(s) that operated, supervised, or controlled the supporting organization.		
<b>2</b>		

**Section C. Type II Supporting Organizations**

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

**Section D. All Type III Supporting Organizations**

	Yes	No
<b>1</b> Did the organization provide to each of its supported organizations, by the last day of the fifth month of the organization's tax year, (i) a written notice describing the type and amount of support provided during the prior tax year, (ii) a copy of the Form 990 that was most recently filed as of the date of notification, and (iii) copies of the organization's governing documents in effect on the date of notification, to the extent not previously provided?		
<b>1</b>		
<b>2</b> Were any of the organization's officers, directors, or trustees either (i) appointed or elected by the supported organization(s), or (ii) serving on the governing body of a supported organization? If "No," explain in <b>Part VI</b> how the organization maintained a close and continuous working relationship with the supported organization(s).		
<b>2</b>		
<b>3</b> By reason of the relationship described on line 2, above, did the organization's supported organizations have a significant voice in the organization's investment policies and in directing the use of the organization's income or assets at all times during the tax year? If "Yes," describe in <b>Part VI</b> the role the organization's supported organizations played in this regard.		
<b>3</b>		

**Section E. Type III Functionally Integrated Supporting Organizations**

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

**Part V Type III Non-Functionally Integrated 509(a)(3) Supporting Organizations**

- 1**  Check here if the organization satisfied the Integral Part Test as a qualifying trust on Nov. 20, 1970 (*explain in Part VI*). **See instructions.** All other Type III non-functionally integrated supporting organizations must complete Sections A through E.

<b>Section A—Adjusted Net Income</b>		(A) Prior Year	(B) Current Year (optional)
<b>1</b>	Net short-term capital gain	<b>1</b>	
<b>2</b>	Recoveries of prior-year distributions	<b>2</b>	
<b>3</b>	Other gross income (see instructions)	<b>3</b>	
<b>4</b>	Add lines 1 through 3.	<b>4</b>	
<b>5</b>	Depreciation and depletion	<b>5</b>	
<b>6</b>	Portion of operating expenses paid or incurred for production or collection of gross income or for management, conservation, or maintenance of property held for production of income (see instructions)	<b>6</b>	
<b>7</b>	Other expenses (see instructions)	<b>7</b>	
<b>8</b>	<b>Adjusted Net Income</b> (subtract lines 5, 6, and 7 from line 4)	<b>8</b>	
<b>Section B—Minimum Asset Amount</b>		(A) Prior Year	(B) Current Year (optional)
<b>1</b>	Aggregate fair market value of all non-exempt-use assets (see instructions for short tax year or assets held for part of year):		
<b>a</b>	Average monthly value of securities	<b>1a</b>	
<b>b</b>	Average monthly cash balances	<b>1b</b>	
<b>c</b>	Fair market value of other non-exempt-use assets	<b>1c</b>	
<b>d</b>	<b>Total</b> (add lines 1a, 1b, and 1c)	<b>1d</b>	
<b>e</b>	<b>Discount</b> claimed for blockage or other factors ( <i>explain in detail in Part VI</i> ):		
<b>2</b>	Acquisition indebtedness applicable to non-exempt-use assets	<b>2</b>	
<b>3</b>	Subtract line 2 from line 1d.	<b>3</b>	
<b>4</b>	Cash deemed held for exempt use. Enter 0.015 of line 3 (for greater amount, see instructions).	<b>4</b>	
<b>5</b>	Net value of non-exempt-use assets (subtract line 4 from line 3)	<b>5</b>	
<b>6</b>	Multiply line 5 by 0.035.	<b>6</b>	
<b>7</b>	Recoveries of prior-year distributions	<b>7</b>	
<b>8</b>	<b>Minimum Asset Amount</b> (add line 7 to line 6)	<b>8</b>	
<b>Section C—Distributable Amount</b>			Current Year
<b>1</b>	Adjusted net income for prior year (from Section A, line 8, column A)	<b>1</b>	
<b>2</b>	Enter 0.85 of line 1.	<b>2</b>	
<b>3</b>	Minimum asset amount for prior year (from Section B, line 8, column A)	<b>3</b>	
<b>4</b>	Enter greater of line 2 or line 3.	<b>4</b>	
<b>5</b>	Income tax imposed in prior year	<b>5</b>	
<b>6</b>	<b>Distributable Amount.</b> Subtract line 5 from line 4, unless subject to emergency temporary reduction (see instructions).	<b>6</b>	
<b>7</b>	<input type="checkbox"/> Check here if the current year is the organization's first as a non-functionally integrated Type III supporting organization (see instructions).		

**Part V** Type III Non-Functionally Integrated 509(a)(3) Supporting Organizations (continued)

Section D—Distributions		Current Year
<b>1</b>	Amounts paid to supported organizations to accomplish exempt purposes	<b>1</b>
<b>2</b>	Amounts paid to perform activity that directly furthers exempt purposes of supported organizations, in excess of income from activity	<b>2</b>
<b>3</b>	Administrative expenses paid to accomplish exempt purposes of supported organizations	<b>3</b>
<b>4</b>	Amounts paid to acquire exempt-use assets	<b>4</b>
<b>5</b>	Qualified set-aside amounts (prior IRS approval required—provide details in <b>Part VI</b> )	<b>5</b>
<b>6</b>	Other distributions (describe in <b>Part VI</b> ). See instructions.	<b>6</b>
<b>7</b>	<b>Total annual distributions.</b> Add lines 1 through 6.	<b>7</b>
<b>8</b>	Distributions to attentive supported organizations to which the organization is responsive (provide details in <b>Part VI</b> ). See instructions.	<b>8</b>
<b>9</b>	Distributable amount for 2023 from Section C, line 6	<b>9</b>
<b>10</b>	Line 8 amount divided by line 9 amount	<b>10</b>

Section E—Distribution Allocations (see instructions)	(i) Excess Distributions	(ii) Underdistributions Pre-2023	(iii) Distributable Amount for 2023
<b>1</b> Distributable amount for 2023 from Section C, line 6			
<b>2</b> Underdistributions, if any, for years prior to 2023 (reasonable cause required—explain in <b>Part VI</b> ). See instructions.			
<b>3</b> Excess distributions carryover, if any, to 2023			
<b>a</b> From 2018 . . . . .			
<b>b</b> From 2019 . . . . .			
<b>c</b> From 2020 . . . . .			
<b>d</b> From 2021 . . . . .			
<b>e</b> From 2022 . . . . .			
<b>f</b> <b>Total</b> of lines 3a through 3e			
<b>g</b> Applied to underdistributions of prior years			
<b>h</b> Applied to 2023 distributable amount			
<b>i</b> Carryover from 2018 not applied (see instructions)			
<b>j</b> Remainder. Subtract lines 3g, 3h, and 3i from line 3f.			
<b>4</b> Distributions for 2023 from Section D, line 7: \$			
<b>a</b> Applied to underdistributions of prior years			
<b>b</b> Applied to 2023 distributable amount			
<b>c</b> Remainder. Subtract lines 4a and 4b from line 4.			
<b>5</b> Remaining underdistributions for years prior to 2023, if any. Subtract lines 3g and 4a from line 2. For result greater than zero, explain in <b>Part VI</b> . See instructions.			
<b>6</b> Remaining underdistributions for 2023. Subtract lines 3h and 4b from line 1. For result greater than zero, explain in <b>Part VI</b> . See instructions.			
<b>7</b> <b>Excess distributions carryover to 2024.</b> Add lines 3j and 4c.			
<b>8</b> Breakdown of line 7:			
<b>a</b> Excess from 2019 . . . . .			
<b>b</b> Excess from 2020 . . . . .			
<b>c</b> Excess from 2021 . . . . .			
<b>d</b> Excess from 2022 . . . . .			
<b>e</b> Excess from 2023 . . . . .			

**Part VI** **Supplemental Information.** Provide the explanations required by Part II, line 10; Part II, line 17a or 17b; Part III, line 12; Part IV, Section A, lines 1, 2, 3b, 3c, 4b, 4c, 5a, 6, 9a, 9b, 9c, 11a, 11b, and 11c; Part IV, Section B, lines 1 and 2; Part IV, Section C, line 1; Part IV, Section D, lines 2 and 3; Part IV, Section E, lines 1c, 2a, 2b, 3a, and 3b; Part V, line 1; Part V, Section B, line 1e; Part V, Section D, lines 5, 6, and 8; and Part V, Section E, lines 2, 5, and 6. Also complete this part for any additional information. (See instructions.)

Pt II Ln 10: Other Income Part II, Line 10 Description: Sales of Merchandise  
Description: Cost of Goods Sold Description: Miscellaneous Revenue 2019: 5000.  
2023: 5350. Description: Family Conference Income 2019: 2500. 2020: 92500. Description:  
Refunds 2019: 16154. 2020: 35989. 2021: 9962.

Schedule B (Form 990)

Department of the Treasury Internal Revenue Service

Schedule of Contributors

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

OMB No. 1545-0047

2023

Table with 2 columns: Name of the organization (International Foundation For CDKL5 Research) and Employer identification number (27-0950477)

Organization type (check one):

Filers of:

Section:

- Form 990 or 990-EZ: [X] 501(c)(3) (enter number) organization, [ ] 4947(a)(1) nonexempt charitable trust not treated as a private foundation, [ ] 527 political organization
Form 990-PF: [ ] 501(c)(3) exempt private foundation, [ ] 4947(a)(1) nonexempt charitable trust treated as a private foundation, [ ] 501(c)(3) taxable private foundation

Check if your organization is covered by the General Rule or a Special Rule.

Note: Only a section 501(c)(7), (8), or (10) organization can check boxes for both the General Rule and a Special Rule. See instructions.

General Rule

- [ ] For an organization filing Form 990, 990-EZ, or 990-PF that received, during the year, contributions totaling \$5,000 or more (in money or property) from any one contributor. Complete Parts I and II. See instructions for determining a contributor's total contributions.

Special Rules

- [X] For an organization described in section 501(c)(3) filing Form 990 or 990-EZ that met the 33 1/3% support test of the regulations under sections 509(a)(1) and 170(b)(1)(A)(vi), that checked Schedule A (Form 990), Part II, line 13, 16a, or 16b, and that received from any one contributor, during the year, total contributions of the greater of (1) \$5,000; or (2) 2% of the amount on (i) Form 990, Part VIII, line 1h; or (ii) Form 990-EZ, line 1. Complete Parts I and II.
[ ] For an organization described in section 501(c)(7), (8), or (10) filing Form 990 or 990-EZ that received from any one contributor, during the year, total contributions of more than \$1,000 exclusively for religious, charitable, scientific, literary, or educational purposes, or for the prevention of cruelty to children or animals. Complete Parts I (entering "N/A" in column (b) instead of the contributor name and address), II, and III.
[ ] For an organization described in section 501(c)(7), (8), or (10) filing Form 990 or 990-EZ that received from any one contributor, during the year, contributions exclusively for religious, charitable, etc., purposes, but no such contributions totaled more than \$1,000. If this box is checked, enter here the total contributions that were received during the year for an exclusively religious, charitable, etc., purpose. Don't complete any of the parts unless the General Rule applies to this organization because it received nonexclusively religious, charitable, etc., contributions totaling \$5,000 or more during the year \$ \_\_\_\_\_

Caution: An organization that isn't covered by the General Rule and/or the Special Rules doesn't file Schedule B (Form 990), but it must answer "No" on Part IV, line 2, of its Form 990; or check the box on line H of its Form 990-EZ or on its Form 990-PF, Part I, line 2, to certify that it doesn't meet the filing requirements of Schedule B (Form 990).

Name of organization International Foundation For CDKL5 Research	Employer identification number 27-0950477
---	--

**Part I** **Contributors** (see instructions). Use duplicate copies of Part I if additional space is needed.

(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
1	Churgin, Miriam Blase 936 New Bedford Drive Marietta GA 300684434	\$ 31,714.	Person <input type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input checked="" type="checkbox"/> (Complete Part II for noncash contributions.)
2	Lauren Mary Francis Foundation 526 Kimball Turn Westfield NJ 070902326	\$ 67,000.	Person <input checked="" type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
3	Koenig, Nathan 1565 Martin Avenue San Jose CA 95126	\$ 26,200.	Person <input checked="" type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
4	Ultragenyx Pharmaceutical 60 Leveroni Ct. Novato CA 94949	\$ 40,000.	Person <input checked="" type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
5	Castellini, Daniel and Joyce 7057 Woodsedge Drive Cincinnati OH 45230	\$ 10,503.	Person <input type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input checked="" type="checkbox"/> (Complete Part II for noncash contributions.)
6	UCB 1950 Lake Park Drive Smyrna GA 30080	\$ 60,000.	Person <input checked="" type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)

Name of organization <u>International Foundation For CDKL5 Research</u>	Employer identification number <u>27-0950477</u>
--	---

**Part II** **Noncash Property** (see instructions). Use duplicate copies of Part II if additional space is needed.

(a) No. from Part I	(b) Description of noncash property given	(c) FMV (or estimate) <small>(See instructions.)</small>	(d) Date received
5.....	<u>250 Comcast Corporation</u> ..... .....	\$ ..... <u>10,503.</u>	..... <u>07/31/2023</u> .....
1.....	<u>255 Fidelity Total Market Index Fund</u> ..... .....	\$ ..... <u>31,714.</u>	..... <u>11/30/2023</u> .....
.....	..... ..... .....	\$ .....	.....
.....	..... ..... .....	\$ .....	.....
.....	..... ..... .....	\$ .....	.....
.....	..... ..... .....	\$ .....	.....
.....	..... ..... .....	\$ .....	.....

Name of organization <b>International Foundation For CDKL5 Research</b>	Employer identification number <b>27-0950477</b>
--	---

**Part III** **Exclusively religious, charitable, etc., contributions to organizations described in section 501(c)(7), (8), or (10) that total more than \$1,000 for the year from any one contributor.** Complete columns (a) through (e) and the following line entry. For organizations completing Part III, enter the total of *exclusively* religious, charitable, etc., contributions of **\$1,000 or less** for the year. (Enter this information once. See instructions.) \$ \_\_\_\_\_  
 Use duplicate copies of Part III if additional space is needed.

(a) No. from Part I	(b) Purpose of gift	(c) Use of gift	(d) Description of how gift is held
-----	----- ----- -----	----- ----- -----	----- ----- -----

(e) Transfer of gift	
Transferee's name, address, and ZIP + 4	Relationship of transferor to transferee
----- ----- -----	----- ----- -----

(a) No. from Part I	(b) Purpose of gift	(c) Use of gift	(d) Description of how gift is held
-----	----- ----- -----	----- ----- -----	----- ----- -----

(e) Transfer of gift	
Transferee's name, address, and ZIP + 4	Relationship of transferor to transferee
----- ----- -----	----- ----- -----

(a) No. from Part I	(b) Purpose of gift	(c) Use of gift	(d) Description of how gift is held
-----	----- ----- -----	----- ----- -----	----- ----- -----

(e) Transfer of gift	
Transferee's name, address, and ZIP + 4	Relationship of transferor to transferee
----- ----- -----	----- ----- -----

(a) No. from Part I	(b) Purpose of gift	(c) Use of gift	(d) Description of how gift is held
-----	----- ----- -----	----- ----- -----	----- ----- -----

(e) Transfer of gift	
Transferee's name, address, and ZIP + 4	Relationship of transferor to transferee
----- ----- -----	----- ----- -----



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

		(a) Event #1	(b) Event #2	(c) Other events	(d) Total events
		Froy (event type)	Ohio Golf (event type)	1 (total number)	(add col. (a) through col. (c))
Revenue	<b>1</b> Gross receipts . . . . .	19,245.	26,822.	11,700.	57,767.
	<b>2</b> Less: Contributions . . . . .	19,245.	25,584.	11,700.	56,529.
	<b>3</b> Gross income (line 1 minus line 2) . . . . .	0.	1,238.	0.	1,238.
Direct Expenses	<b>4</b> Cash prizes . . . . .				
	<b>5</b> Noncash prizes . . . . .				
	<b>6</b> Rent/facility costs . . . . .				
	<b>7</b> Food and beverages . . . . .				
	<b>8</b> Entertainment . . . . .				
	<b>9</b> Other direct expenses . . . . .		1,238.		1,238.
	<b>10</b> Direct expense summary. Add lines 4 through 9 in column (d) . . . . .				1,238.
<b>11</b> Net income summary. Subtract line 10 from line 3, column (d) . . . . .				0.	

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

		(a) Bingo	(b) Pull tabs/instant bingo/progressive bingo	(c) Other gaming	(d) Total gaming (add col. (a) through col. (c))
		Revenue	<b>1</b> Gross revenue . . . . .		
Direct Expenses	<b>2</b> Cash prizes . . . . .				
	<b>3</b> Noncash prizes . . . . .				
	<b>4</b> Rent/facility costs . . . . .				
	<b>5</b> Other direct expenses . . . . .				
	<b>6</b> 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	
<b>7</b> Direct expense summary. Add lines 2 through 5 in column (d) . . . . .					
<b>8</b> Net gaming income summary. Subtract line 7 from line 1, column (d) . . . . .					

**9** Enter the state(s) in which the organization conducts gaming activities: \_\_\_\_\_

**a** Is the organization licensed to conduct gaming activities in each of these states?  Yes  No

**b** If "No," explain: \_\_\_\_\_

\_\_\_\_\_

**10a** Were any of the organization's gaming licenses revoked, suspended, or terminated during the tax year?  Yes  No

**b** If "Yes," explain: \_\_\_\_\_

\_\_\_\_\_



**SCHEDULE I  
(Form 990)**

Department of the Treasury  
Internal Revenue Service

Name of the organization

International Foundation For CDKL5 Research

**Part I General Information on Grants and Assistance**

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

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

1 (a) Name and address of organization or government	(b) EIN	(c) IRC section (if applicable)	(d) Amount of cash grant	(e) Amount of noncash assistance	(f) Method of valuation (book, FMV, appraisal, other)	(g) Description of noncash assistance	(h) Purpose of grant or assistance
<b>(1)</b> Children's Hospital, Philadelphia 3401 Civic Center Blvd Philadelphia PA 19104	23-1352166	501 (c) (3)	50,000.	0.	N/A	N/a	Research
<b>(2)</b> Boston Children's Hospital 1295 Boylston Street Boston MA 02215	53-0196580	501 (c) (3)	72,884.	0.	N/A	N/A	72884
<b>(3)</b> Vanderbilt University Medical Center 3319 West End Avenue, Suite 900 Nashville TN 37203	35-2528741	501 (c) (3)	35,000.	0.	N/A	N/A	35000
<b>(4)</b> NYU School of Medicine 550 1st Avenue New York NY 10016	13-3971298	501 (c) (3)	25,000.	0.	N/A	N/A	25000
<b>(5)</b> Urban Disease Center at University of Pennsylvania 125 South 31st Street Philadelphia PA 19104	23-1352685	501 (c) (3)	10,000.	0.	N/A	N/A	10000
<b>(6)</b> .....							
<b>(7)</b> .....							
<b>(8)</b> .....							
<b>(9)</b> .....							
<b>(10)</b> .....							
<b>(11)</b> .....							
<b>(12)</b> .....							

**2** Enter total number of section 501(c)(3) and government organizations listed in the line 1 table ..... 5

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

Employer identification number  
27-0950477

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

Attach to Form 990.

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

	(a) Type of grant or assistance	(b) Number of recipients	(c) Amount of cash grant	(d) Amount of non-cash assistance	(e) Method of valuation (book, FMV, appraisal, other)	(f) Description of non-cash assistance
1						
2						
3						
4						
5						
6						
7						

**Part IV Supplemental Information.** Provide the information required in Part I, line 2; Part III, column (b); and any other additional information.

Pt I Line 2: A group of officers monitors how these funds are being used on a

Pt I Line 2: frequent basis.

**SCHEDULE M  
(Form 990)**

**Noncash Contributions**

OMB No. 1545-0047

**2023**

**Open to Public Inspection**

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

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

Department of the Treasury  
Internal Revenue Service

Name of the organization

Employer identification number

International Foundation For CDKL5 Research

27-0950477

**Part I Types of Property**

	(a) Check if applicable	(b) Number of contributions or items contributed	(c) Noncash contribution amounts reported on Form 990, Part VIII, line 1g	(d) Method of determining noncash contribution amounts
1				
2				
3				
4				
5				
6				
7				
8				
9	X	2	42,217.	Fair Market Value
10				
11				
12				
13				
14				
15				
16				
17				
18				
19				
20				
21				
22				
23				
24				
25				
26				
27				
28				

29 Number of Forms 8283 received by the organization during the tax year for contributions for which the organization completed Form 8283, Part V, Donee Acknowledgement . . . . .

29

30a During the year, did the organization receive by contribution any property reported in Part I, lines 1 through 28, that it must hold for at least 3 years from the date of the initial contribution, and which isn't required to be used for exempt purposes for the entire holding period? . . . . .

	Yes	No
30a		X

b If "Yes," describe the arrangement in Part II.

31 Does the organization have a gift acceptance policy that requires the review of any nonstandard contributions? . . . . .

31	X	
----	---	--

32a Does the organization hire or use third parties or related organizations to solicit, process, or sell noncash contributions? . . . . .

32a		X
-----	--	---

b If "Yes," describe in Part II.

33 If the organization didn't report an amount in column (c) for a type of property for which column (a) is checked, describe in Part II.



**SCHEDULE O  
(Form 990)**

**Supplemental Information to Form 990 or 990-EZ**

OMB No. 1545-0047

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

**2023**

Attach to Form 990 or Form 990-EZ.

**Open to Public Inspection**

Department of the Treasury  
Internal Revenue Service

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

Name of the organization

Employer identification number

International Foundation For CDKL5 Research

27-0950477

Pt VI, Line 11b: The form is reviewed by the Board Treasurer and other

Pt VI, Line 11b: members of the Board. All questions are reviewed to make

Pt VI, Line 11b: certain that there are no incorrect answers.

Pt VI, Line 12c: Questionnaires are required to be completed by all

Pt VI, Line 12c: Board members annually. Should there be reasons for

Pt VI, Line 12c: concern, there is a detailed review of all

Pt VI, Line 12c: transactions that appear to be a cause for concern.

Pt VI, Line 19: Upon request, they are provided to grantors, contributors,

Pt VI, Line 19: and Board members.

Pt IX, Line 11g:

Description: Outside Contract Services

Total: \$72,598

Program services: \$72,598

Management and general: \$0

Fundraising: \$0

Description: Science Consultant

Total: \$68,750

Program services: \$68,750

Management and general: \$0

Fundraising: \$0

Pt IX, Line 24e:

Description: Donor Management

Total: \$11,106

Program services: \$5,109

Management and general: \$888

Name of the organization International Foundation For CDKL5 Research	Employer identification number 27-0950477
---	--

Fundraising: \$5,109

Description: Family Support

Total: \$35,323

Program services: \$35,323

Management and general: \$0

Fundraising: \$0

Description: Fundraising Fees

Total: \$3,678

Program services: \$0

Management and general: \$0

Fundraising: \$3,678

Description: Memberships & Dues

Total: \$925

Program services: \$925

Management and general: \$0

Fundraising: \$0

Description: Printing

Total: \$2,475

Program services: \$2,475

Management and general: \$0

Fundraising: \$0

Description: Telephone

Total: \$662

Program services: \$397

Management and general: \$66

Fundraising: \$199

Description: Volunteer Appreciation

Name of the organization

Employer identification number

International Foundation For CDKL5 Research

27-0950477

Total: \$294

Program services: \$294

Management and general: \$0

Fundraising: \$0





**Additional Information From 2023 Federal Exempt Tax Return****Schedule A: Public Charity Status and Public Support****Gross Receipts****Itemization Statement**

<b>Description</b>	<b>Amount</b>
2019 - Family Conference Income	2,500.
2020 - Family Conference Income	92,500.
<b>Total</b>	<b>95,000.</b>

# IRS E-file Signature Authorization for a Tax Exempt Entity

For calendar year 2023, or fiscal year beginning \_\_\_\_\_, 2023, and ending \_\_\_\_\_, 20\_\_\_\_\_

# 2023

Department of the Treasury  
Internal Revenue Service

**Do not send to the IRS. Keep for your records.**  
Go to [www.irs.gov/Form8879TE](http://www.irs.gov/Form8879TE) for the latest information.

Name of filer

EIN or SSN

International Foundation For CDKL5 Research

27-0950477

Name and title of officer or person subject to tax

Karen Utley, President

## Part I Type of Return and Return Information

Check the box for the return for which you are using this Form 8879-TE and enter the applicable amount, if any, from the return. Form 8038-CP and Form 5330 filers may enter dollars and cents. For all other forms, enter whole dollars only. If you check the box on line 1a, 2a, 3a, 4a, 5a, 6a, 7a, 8a, 9a, or 10a below, and the amount on that line for the return being filed with this form was blank, then leave line 1b, 2b, 3b, 4b, 5b, 6b, 7b, 8b, 9b, or 10b, whichever is applicable, blank (do not enter -0-). But, if you entered -0- on the return, then enter -0- on the applicable line below. **Do not** complete more than one line in Part I.

1a	Form 990 check here	<input checked="" type="checkbox"/>	b	Total revenue, if any (Form 990, Part VIII, column (A), line 12)	1b	<u>639,182.</u>
2a	Form 990-EZ check here	<input type="checkbox"/>	b	Total revenue, if any (Form 990-EZ, line 9)	2b	_____
3a	Form 1120-POL check here	<input type="checkbox"/>	b	Total tax (Form 1120-POL, line 22)	3b	_____
4a	Form 990-PF check here	<input type="checkbox"/>	b	Tax based on investment income (Form 990-PF, Part V, line 5)	4b	_____
5a	Form 8868 check here	<input type="checkbox"/>	b	Balance due (Form 8868, line 3c)	5b	_____
6a	Form 990-T check here	<input type="checkbox"/>	b	Total tax (Form 990-T, Part III, line 4)	6b	_____
7a	Form 4720 check here	<input type="checkbox"/>	b	Total tax (Form 4720, Part III, line 1)	7b	_____
8a	Form 5227 check here	<input type="checkbox"/>	b	FMV of assets at end of tax year (Form 5227, Item D)	8b	_____
9a	Form 5330 check here	<input type="checkbox"/>	b	Tax due (Form 5330, Part II, line 19)	9b	_____
10a	Form 8038-CP check here	<input type="checkbox"/>	b	Amount of credit payment requested (Form 8038-CP, Part III, line 22)	10b	_____

## Part II Declaration and Signature Authorization of Officer or Person Subject to Tax

Under penalties of perjury, I declare that  I am an officer of the above entity or  I am a person subject to tax with respect to (name of entity) \_\_\_\_\_, (EIN) \_\_\_\_\_ and that I have examined a copy of the 2023 electronic return and accompanying schedules and statements, and, to the best of my knowledge and belief, they are true, correct, and complete. I further declare that the amount in Part I above is the amount shown on the copy of the electronic return. I consent to allow my intermediate service provider, transmitter, or electronic return originator (ERO) to send the return to the IRS and to receive from the IRS (a) an acknowledgement of receipt or reason for rejection of the transmission, (b) the reason for any delay in processing the return or refund, and (c) the date of any refund. If applicable, I authorize the U.S. Treasury and its designated Financial Agent to initiate an electronic funds withdrawal (direct debit) entry to the financial institution account indicated in the tax preparation software for payment of the federal taxes owed on this return, and the financial institution to debit the entry to this account. To revoke a payment, I must contact the U.S. Treasury Financial Agent at 1-888-353-4537 no later than 2 business days prior to the payment (settlement) date. I also authorize the financial institutions involved in the processing of the electronic payment of taxes to receive confidential information necessary to answer inquiries and resolve issues related to the payment. I have selected a personal identification number (PIN) as my signature for the electronic return and, if applicable, the consent to electronic funds withdrawal.

### PIN: check one box only

I authorize JUDY L. ARFA, CPA PLLC to enter my PIN 

5	5	3	4	4
---	---	---	---	---

 as my signature  
ERO firm name Enter five numbers, but do not enter all zeros

on the tax year 2023 electronically filed return. If I have indicated within this return that a copy of the return is being filed with a state agency(ies) regulating charities as part of the IRS Fed/State program, I also authorize the aforementioned ERO to enter my PIN on the return's disclosure consent screen.

As an officer or person subject to tax with respect to the entity, I will enter my PIN as my signature on the tax year 2023 electronically filed return. If I have indicated within this return that a copy of the return is being filed with a state agency(ies) regulating charities as part of the IRS Fed/State program, I will enter my PIN on the return's disclosure consent screen.

Signature of officer or person subject to tax  Date 10/20/24

## Part III Certification and Authentication

ERO's EFIN/PIN. Enter your six-digit electronic filing identification number (EFIN) followed by your five-digit self-selected PIN.

7	6	1	7	3	9	5	2	9	8	6
---	---	---	---	---	---	---	---	---	---	---

Do not enter all zeros

I certify that the above numeric entry is my PIN, which is my signature on the 2023 electronically filed return indicated above. I confirm that I am submitting this return in accordance with the requirements of **Pub. 4163**, Modernized e-File (MeF) Information for Authorized IRS e-file Providers for Business Returns.

ERO's signature  Date 10/20/2024

**ERO Must Retain This Form — See Instructions**  
**Do Not Submit This Form to the IRS Unless Requested To Do So**