

990

Return of Organization Exempt From Income Tax

OMB No. 1545-

0047 2024

Open to Public Inspection

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.

Department of the Treasury Internal Revenue Service

A For the 2024 calendar year, or tax year beginning 01-01-2024, and ending 12-31-2024

- B Check if applicable: Address change, Name change, Initial return, Final return/terminated, Amended return, Application pending

C Name of organization: CONGENITAL HYPERINSULINISM INTERNATIONAL. Doing business as. Number and street (or P.O. box if mail is not delivered to street address) Room/suite: PO BOX 135. City or town, state or province, country, and ZIP or foreign postal code: GLEN RIDGE, NJ 07028

D Employer identification number: 20-3068945. E Telephone number: (973) 566-0334. G Gross receipts \$ 1,330,299

F Name and address of principal officer: PO BOX 135, GLEN RIDGE, NJ 07028

H(a) Is this a group return for subordinates? No. H(b) Are all subordinates included? No. H(c) Group exemption number

I Tax-exempt status: 501(c)(3)

J Website: www.congenitalhi.org

K Form of organization: Corporation

L Year of formation: 2006. M State of legal domicile: NM

Part I Summary

Table with 3 main sections: 1. Activities & Governance (mission statement, 2-7b); 2. Revenue (8-12); 3. Expenses (13-19). Includes a sub-table for Net Assets or Fund Balances (20-22) with columns for Prior Year, Current Year, Beginning of Current Year, and End of Year.

Part II Signature Block

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

Sign Here: Signature of officer JULIE SHELDON Treasurer, Date 2025-09-18

Paid Preparer Use Only: Print/Type preparer's name MAUREEN A LEIDL CPA, Preparer's signature, Date, Check if self-employed, PTIN P00847064, Firm's name, Firm's EIN 27-2133606, Firm's address 223 LORRAINE AVE, MONTCLAIR, NJ 07043, Phone no. (973) 783-2000

May the IRS discuss this return with the preparer shown above? See Instructions. 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:

Congenital Hyperinsulinism International (CHI) is a nonprofit 501(c)(3) corporation dedicated to improving the lives of babies, children, and adults affected by congenital hyperinsulinism (HI). HI is a life-threatening genetic disorder that causes severe low blood sugar (hypoglycemia) in infants and children, though in 50% of patients, the genetic cause is unknown. For those with HI, the beta cells of the pancreas secrete too much insulin in an unregulated manner. Excess insulin causes hypoglycemia. Prolonged or severe hypoglycemia can cause seizures, permanent brain damage, or even death if left untreated. A good prognosis is far more likely with a timely diagnosis and proper management.

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 \$ 571,274 including grants of \$ ) (Revenue \$ )

CHI supports research and development to better understand, treat, manage, and hopefully cure HI. CHI shares the patient perspective with researchers and members of the biopharmaceutical industry to accelerate the development of patient-centered treatments. CHI is a part of the Million Dollar Bike Ride grant program with the University of Pennsylvanias Center for Orphan Diseases; a pilot research grant is offered each year for an innovative, preclinical or clinical study with the potential to lead to a better HI treatment, a cure for HI, or improvement in the quality of life for those affected by HI. In 2024, CHI was able to award two pilot research grants through this program. In 2024, the CHI Research Staff worked with a lead epidemiologist to publish The Birth Prevalence of Congenital Hyperinsulinism: A Narrative Review of the Epidemiology of a Rare Disease. This publication, published in Hormone Research in Pediatrics, reviews epidemiological data on HI as reported in the literature, identifying the strengths and limitations of each HI prevalence study. CHI conducts the HI Global Registry (HIGR) research project. HIGR provides a convenient online platform for the HI patient community to share their experiences of living with HI. With permission from the patient families, MaxHIGR provides complementary data from the physician perspective. By participating in the HI Global Registry, the patient community helps themselves and researchers better understand HI to advance better treatments, a potential cure, and more timely and accurate diagnoses. A HIGR report is published each year by the CHI staff. Scholars and research may request deidentified data for their research projects. In 2024, CHI continued to lead the Collaborative Research Network (CRN), a project of CHI dedicated to the development of faster and more accurate diagnoses, new evidence-based treatments and cures, standardized clinical guidelines, and increased and improved access to treatment, medication, devices, and supplies. This ambitious project includes working groups focused on different aspects of a prioritized research agenda (PRA) developed by the CRNs members including 60 leading researchers, clinicians, and patient advocates from 17 countries. The CRN members have been focused on the top priorities identified in the PRA: Newborn Screening (Diagnose all babies with congenital hyperinsulinism in a timely manner); Glucose as a Vital Sign (Increase awareness and timely diagnosis of HI); Care Guidelines (Create and disseminate continually evolving global care guidelines); Natural History (Build a robust registry that collects patient-reported, physician, and real-world data to provide a foundation for HI natural history); Continuous Glucose Monitoring (Create principles for Draft guidelines on CGM use in HI patients). Since the launch of the CRN in 2020, the CRN members have published a total of 194 articles on congenital hyperinsulinism covering a wide range of topics including genetics, treatment, disease management, monitoring and technology, screening and diagnostics, clinical guidelines, education, patient experience, quality of life, policy, and access to care. In 2024, the CRN published an Advocacy Statement and List of Essential Medical Care, Medication, Supplies, and Services for people with congenital hyperinsulinism (HI). The CRN also published "Continuous glucose monitoring for children and young people with hyperinsulinism: a practical guide for families & professionals and CGM: a tool to support HI families". These guides are a collaboration of work by HI experts around the world, including many who are part of the CHI CRN and CHI staff. Patient and caregiver representatives of the CHI CRN provided the patient perspective. CHI continues to support the Open Hyperinsulinism Genes Program in partnership with the University of Exeter in the UK. This program is the first point-of-need international genetic testing service for HI and is also accelerating scientific knowledge through the creation of a self-sustaining research gene discovery pipeline. Through December 2024, 1001 samples from individuals affected by Congenital Hyperinsulinism and 731 samples from family members from 63 countries on 5 continents have been tested. In 2024, CHI continued to support the CHI Centers of Excellence Designation and announced a second round of designations. Eight centers were granted the designation, or re-designated, and recognized as multi-disciplinary clinical and research centers in the field of congenital hyperinsulinism. The goals of this program are to make it easier for patient families to access care at leading hospitals, encourage patient-focused standards at the leading hospitals, foster a pipeline of expert clinicians and researchers, and to encourage collaboration among researchers, clinicians, and patient leaders and advocates. In 2024, CHI became a part of the international, 11-member LightCure Consortium, a project made possible by a grant from the European Union research arm Horizon Europe and encompassing CHIs work to strengthen patient engagement and raise worldwide awareness of HI and its myriad of challenges. The scientific researchers who are a part of the LightCure consortium hypothesize that via a minimally invasive process, light can be used to target and eliminate improperly working pancreatic cells.

4b (Code: ) (Expenses \$ 226,850 including grants of \$ ) (Revenue \$ )

CHI increases awareness of HI to improve timely diagnosis and guideline-driven management of HI to the public and medical personnel who have a direct opportunity to detect it, in order to decrease adverse neurological outcomes and death. To that end, CHI spreads awareness of HI with ongoing campaigns on social media, the CHI website and blog, CHI posters in 25 languages, CHI brochures, through direct mail and email, and at meetings and conferences. CHI provides educational resources and holds conferences and meetings on HI for patients, families, medical professionals, school personnel, and rare disease industry members. To date, CHI has held 35 family and research meetings and conferences with presentations from academic researchers, members of advocacy organizations, HI patients and families, and biotechnology companies.

4c (Code: ) (Expenses \$ 194,143 including grants of \$ ) (Revenue \$ )

CHI advocates on behalf of HI families all over the world for access to quality treatment, medication, and supplies. CHI provides opportunities for affected families to emotionally support each other because the home care medical management of HI is often complicated and difficult. CHI offers online forums, and CHI staff and volunteers are available by telephone, virtually and in-person for support. CHI establishes funds at hospitals to support families from out of town who must travel to centers of excellence for patient care.

4d Other program services (Describe in Schedule O.) (Expenses \$ including grants of \$ ) (Revenue \$ )

4e Total program service expenses 992,267

Part IV Checklist of Required Schedules

Table with 3 columns: Question ID, Question Text, Yes, No. Rows include questions 1 through 21 regarding organizational requirements, such as completing Schedules A through H, and specific rules for 501(c)(3) organizations.

**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>		No
<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>		No
<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>		No
<b>24b</b>	Did the organization invest any proceeds of tax-exempt bonds beyond a temporary period exception? . . . . .		
<b>24c</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>24d</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>		No
<b>25b</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>		No
<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?		No
<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>		No
<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>28a</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>		No
<b>28b</b>	A family member of any individual described in line 28a? <i>If "Yes," complete Schedule L, Part IV . . . . .</i>		No
<b>28c</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>		No
<b>29</b>	Did the organization receive more than \$25,000 in non-cash contributions? <i>If "Yes," complete Schedule M . . . . .</i>		No
<b>30</b>	Did the organization receive contributions of art, historical treasures, or other similar assets, or qualified conservation contributions?		No
<b>31</b>	Did the organization liquidate, terminate, or dissolve and cease operations? <i>If "Yes," complete Schedule N, Part I</i>		No
<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>		No
<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?		No
<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>		No
<b>35a</b>	Did the organization have a controlled entity within the meaning of section 512(b)(13)?		No
<b>35b</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>		
<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>		No
<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>		No
<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. . . . .	Yes	

**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>1b</b>	Enter the number of Forms W-2G included on line 1a. Enter -0- if not applicable		
<b>1c</b>	Did the organization comply with backup withholding rules for reportable payments to vendors and reportable gaming (gambling) winnings to prize winners? . . . . .	Yes	

Part V Statements Regarding Other IRS Filings and Tax Compliance (continued)

Main form area containing questions 2a through 17, with sub-questions and input fields for 'Yes', 'No', and numerical values.

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



Section A. Governing Body and Management

Table with 3 columns: Question, Yes, No. Rows include: 1a Enter the number of voting members... 1b Enter the number of voting members... 2 Did any officer, director, trustee... 3 Did the organization delegate control... 4 Did the organization make any significant changes... 5 Did the organization become aware... 6 Did the organization have members... 7a Did the organization have members... 7b Are any governance decisions... 8 Did the organization contemporaneously document... 8a The governing body? 8b Each committee... 9 Is there any officer, director, trustee, or key employee listed in Part VII...

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

Table with 3 columns: Question, Yes, No. Rows include: 10a Did the organization have local chapters... 10b If "Yes," did the organization have written policies... 11a Has the organization provided a complete copy... 11b Describe on Schedule O the process... 12a Did the organization have a written conflict of interest policy... 12b Were officers, directors, or trustees... 12c Did the organization regularly and consistently monitor... 13 Did the organization have a written whistleblower policy... 14 Did the organization have a written document retention... 15 Did the process for determining compensation... 15a The organization's CEO... 15b Other officers or key employees... 16a Did the organization invest in, contribute assets to... 16b If "Yes," did the organization follow a written policy...

Section C. Disclosure

Table with 3 columns: Question, Yes, No. Rows include: 17 List the states with which a copy of this Form 990 is required to be filed CA, CO, CT, FL, IL, MA, MD, NJ, NM, NY, PA, VA 18 Section 6104 requires an organization to make its Form 1023... 19 Describe in Schedule O whether (and if so, how) the organization made its governing documents... 20 State the name, address, and telephone number of the person who possesses the organization's books and records: JENNIFER SCHMITT PO BOX 135 GLEN RIDGE, NJ 07028 (973) 544-8372





**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
Contributions, Gifts, Grants, and Other Amt Similar Amounts				
<b>1a</b> Federated campaigns . . . . .		<b>1a</b>		
<b>b</b> Membership dues . . . . .		<b>1b</b>		
<b>c</b> Fundraising events . . . . .		<b>1c</b>	139,686	
<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>	120,485	
<b>g</b> Noncash contributions included in lines 1a - 1f:\$		<b>1g</b>		
<b>h Total.</b> Add lines 1a-1f . . . . .				260,171

Program Service Revenue		Business Code			
<b>2a</b> CONFERENCES			103,700		103,700
<b>b</b> RESEARCH			874,410		874,410
<b>c</b>					
<b>d</b>					
<b>e</b>					
<b>f</b> All other program service revenue.					
<b>g Total.</b> Add lines 2a-2f. . . . .			978,110		

Other Revenue	<b>3</b> Investment income (including dividends, interest, and other similar amounts)		63,858	63,858		
	<b>4</b> Income from investment of tax-exempt bond proceeds		0			
	<b>5</b> Royalties . . . . .		0			
	<b>6a</b> Gross rents	(i) Real				
		(ii) Personal				
		<b>6b</b> Less: rental expenses				
		<b>6c</b> Rental income or (loss)				
	<b>d</b> Net rental income or (loss) . . . . .		0			
	<b>7a</b> Gross amount from sales of assets other than inventory	(i) Securities				
		(ii) Other				
		<b>7b</b> Less: cost or other basis and sales expenses				
		<b>7c</b> Gain or (loss)				
	<b>d</b> Net gain or (loss) . . . . .		0			
	<b>8a</b> Gross income from fundraising events (not including \$ 139,686 of contributions reported on line 1c). See Part IV, line 18 . . . . .					
		<b>8a</b>	27,000			
<b>8b</b> Less: direct expenses		54,525				
<b>c</b> Net income or (loss) from fundraising events . . . . .		-27,525				
<b>9a</b> Gross income from gaming activities. See Part IV, line 19 . . . . .						
	<b>9a</b>					
	<b>9b</b> Less: direct expenses					
<b>c</b> Net income or (loss) from gaming activities . . . . .		0				
<b>10a</b> Gross sales of inventory, less returns and allowances . . . . .						
	<b>10a</b>					
	<b>10b</b> Less: cost of goods sold					
<b>c</b> Net income or (loss) from sales of inventory . . . . .		0				

Other Revenue Misc Amt	<b>11a</b> Misc revenue	Business Code			
		900099	1,160	1,160	
	<b>b</b>				
	<b>c</b>				
	<b>d</b> All other revenue . . . . .				
<b>e Total.</b> Add lines 11a-11d . . . . .			1,160		
<b>12 Total revenue.</b> See instructions . . . . .			1,275,774	65,018	978,110

**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

<b>Do not include amounts reported on lines 6b, 7b, 8b, 9b, and 10b of Part VIII.</b>	<b>(A)</b> Total expenses	<b>(B)</b> Program service expenses	<b>(C)</b> Management and general expenses	<b>(D)</b> Fundraising expenses
<b>1</b> Grants and other assistance to domestic organizations and domestic governments. See Part IV, line 21	76,715	76,715		
<b>2</b> Grants and other assistance to domestic individuals. See Part IV, line 22	0			
<b>3</b> Grants and other assistance to foreign organizations, foreign governments, and foreign individuals. See Part IV, lines 15 and 16.	32,382	32,382		
<b>4</b> Benefits paid to or for members	0			
<b>5</b> Compensation of current officers, directors, trustees, and key employees	299,071	244,757	33,907	20,407
<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)	0			
<b>7</b> Other salaries and wages	217,354	187,786		29,568
<b>8</b> Pension plan accruals and contributions (include section 401(k) and 403(b) employer contributions)	0			
<b>9</b> Other employee benefits	0			
<b>10</b> Payroll taxes	65,316	54,707	4,289	6,320
<b>11</b> Fees for services (non-employees):				
<b>a</b> Management	0			
<b>b</b> Legal	0			
<b>c</b> Accounting	0			
<b>d</b> Lobbying	0			
<b>e</b> Professional fundraising services. See Part IV, line 17	0			
<b>f</b> Investment management fees	0			
<b>g</b> Other (If line 11g amount exceeds 10% of line 25, column (A) amount, list line 11g expenses on Schedule O)	33,091	17,238	12,988	2,865
<b>12</b> Advertising and promotion	0			
<b>13</b> Office expenses	6,049	3,924	1,035	1,090
<b>14</b> Information technology	0			
<b>15</b> Royalties	0			
<b>16</b> Occupancy	0			
<b>17</b> Travel	17,088	17,088		
<b>18</b> Payments of travel or entertainment expenses for any federal, state, or local public officials	0			
<b>19</b> Conferences, conventions, and meetings	128,652	128,652		
<b>20</b> Interest	0			
<b>21</b> Payments to affiliates	0			
<b>22</b> Depreciation, depletion, and amortization	22,670	22,670		
<b>23</b> Insurance	7,319	3,525	1,863	1,931
<b>24</b> Other expenses. Itemize expenses not covered above (List miscellaneous expenses in line 24e. If line 24e amount exceeds 10% of line 25, column (A) amount, list line 24e expenses on Schedule O.)				
<b>a</b> PROGRAM COSTS AND MATERIALS	129,149	129,149		
<b>b</b> TELECOMMUNICATION & TECHNOLOGY	37,850	22,709	4,576	10,565
<b>c</b> CLINICAL RESEARCH EXPENSES	37,446	37,446		
<b>d</b> TRANSLATION FEES	7,038	7,038		
<b>e</b> All other expenses	9,665	6,481	1,184	2,000
<b>25</b> <b>Total functional expenses.</b> Add lines 1 through 24e	1,126,855	992,267	59,842	74,746
<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 IX

		(A) Beginning of year		(B) End of year
<b>Assets</b>	<b>1</b> Cash-non-interest-bearing . . . . .	1,595,342	<b>1</b>	2,012,346
	<b>2</b> Savings and temporary cash investments		<b>2</b>	0
	<b>3</b> Pledges and grants receivable, net . . . . .	64,759	<b>3</b>	58,885
	<b>4</b> Accounts receivable, net . . . . .		<b>4</b>	0
	<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>	0
	<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>	0
	<b>7</b> Notes and loans receivable, net . . . . .		<b>7</b>	0
	<b>8</b> Inventories for sale or use . . . . .		<b>8</b>	0
	<b>9</b> Prepaid expenses and deferred charges . . . . .	31,746	<b>9</b>	13,918
	<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> 0
	<b>11</b> Investments—publicly traded securities . . . . .		<b>11</b>	0
	<b>12</b> Investments—other securities. See Part IV, line 11 . . . . .		<b>12</b>	0
	<b>13</b> Investments—program-related. See Part IV, line 11 . . . . .		<b>13</b>	0
	<b>14</b> Intangible assets . . . . .	111,476	<b>14</b>	88,806
	<b>15</b> Other assets. See Part IV, line 11		<b>15</b>	0
<b>16 Total assets:</b> Add lines 1 through 15 (must equal line 33) . . . . .	1,803,323	<b>16</b>	2,173,955	
<b>Liabilities</b>	<b>17</b> Accounts payable and accrued expenses . . . . .	98,789	<b>17</b>	320,502
	<b>18</b> Grants payable . . . . .		<b>18</b>	
	<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 . . . . .	98,789	<b>26</b>	320,502	
<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 . . . . .	1,669,534	<b>27</b>	1,853,453
	<b>28</b> Net assets with donor restrictions	35,000	<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	1,704,534	<b>32</b>	1,853,453
<b>33</b> Total liabilities and net assets/fund balances	1,803,323	<b>33</b>	2,173,955	

**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>	1,275,774
<b>2</b>	Total expenses (must equal Part IX, column (A), line 25)	<b>2</b>	1,126,855
<b>3</b>	Revenue less expenses. Subtract line 2 from line 1	<b>3</b>	148,919
<b>4</b>	Net assets or fund balances at beginning of year (must equal Part X, line 32, column (A))	<b>4</b>	1,704,534
<b>5</b>	Net unrealized gains (losses) on investments	<b>5</b>	
<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>	
<b>9</b>	Other changes in net assets or fund balances (explain in 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 (A))	<b>10</b>	1,853,453

**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		No
<b>2b</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 checked="" type="checkbox"/> Separate basis <input type="checkbox"/> Consolidated basis <input type="checkbox"/> Both consolidated and separate basis	Yes	
<b>2c</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 in Schedule O.	Yes	
<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?		No
<b>3b</b>	If "Yes," did the organization undergo the required audit or audits? If the organization did not undergo the required audit or audits, explain why in Schedule O and describe any steps taken to undergo such audits.		

**Additional Data**

[Return to Form](#)

**Software ID:** 24020490

**Software Version:** 2024v5.2

**Form 990, Special Condition Description:**

**Special Condition Description**

**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.**

**Name of the organization**  
CONGENITAL HYPERINSULINISM INTERNATIONAL

**Employer identification number**  
20-3068945

**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)(vi).** (Complete Part II.)
- 9  An agricultural research organization described in **170(b)(1)(A)(ix)** operated in conjunction with a land-grant college or university or a non-land grant college of agriculture. See instructions. Enter the name, city, and state of the college or university:
- 10  An organization that normally receives: (1) more than 33 1/3% of its support from contributions, membership fees, and gross receipts from activities related to its exempt functions—subject to certain exceptions, and (2) no more than 33 1/3% of its support from gross investment income and unrelated business taxable income (less section 511 tax) from businesses acquired by the organization after June 30, 1975. See **section 509(a)(2).** (Complete Part III.)
- 11  An organization organized and operated exclusively to test for public safety. See **section 509(a)(4).**
- 12  An organization organized and operated exclusively for the benefit of, to perform the functions of, or to carry out the purposes of one or more publicly supported organizations described in **section 509(a)(1)** or **section 509(a)(2).** See **section 509(a)(3).** Check the box 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		
<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 failed to qualify under the tests listed below, please complete Part III.)

**Section A. Public Support**

Calendar year (or fiscal year beginning in) ▶	(a) 2020	(b) 2021	(c) 2022	(d) 2023	(e) 2024	(f) Total
<b>1</b> Gifts, grants, contributions, and membership fees received. (Do not include any "unusual grant.") . . .	634,893	804,129	477,854	463,103	157,681	2,537,660
<b>2</b> Tax revenues levied for the organization's benefit and either paid to or expended on its behalf . . . . .						0
<b>3</b> The value of services or facilities furnished by a governmental unit to the organization without charge..						0
<b>4 Total.</b> Add lines 1 through 3	634,893	804,129	477,854	463,103	157,681	2,537,660
<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) . . .						218,960
<b>6 Public support.</b> Subtract line 5 from line 4.						2,318,700

**Section B. Total Support**

Calendar year (or fiscal year beginning in) ▶	(a) 2020	(b) 2021	(c) 2022	(d) 2023	(e) 2024	(f) Total
<b>7</b> Amounts from line 4. . . . .	634,893	804,129	477,854	463,103	157,681	2,537,660
<b>8</b> Gross income from interest, dividends, payments received on securities loans, rents, royalties and income from similar sources . . . . .				25,235	63,858	89,093
<b>9</b> Net income from unrelated business activities, whether or not the business is regularly carried on . . . . .						0
<b>10</b> Other income. Do not include gain or loss from the sale of capital assets (Explain in Part VI.) . . . . .						0
<b>11 Total support.</b> Add lines 7 through 10						2,626,753
<b>12</b> Gross receipts from related activities, etc. (see instructions) . . . . .					<b>12</b>	2,485,320
<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 2024 (line 6, column (f) divided by line 11, column (f)) . . . . .	<b>14</b>	88.270 %
<b>15</b> Public support percentage for 2023 Schedule A, Part II, line 14 . . . . .	<b>15</b>	92.810 %
<b>16a 33 1/3% support test—2024.</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—2023.</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—2024.</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—2023.</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

Table with 7 columns: (a) 2020, (b) 2021, (c) 2022, (d) 2023, (e) 2024, (f) Total. Rows include: 1 Gifts, grants, contributions, and membership fees received; 2 Gross receipts from admissions, merchandise sold or services performed; 3 Gross receipts from activities that are not an unrelated trade or business; 4 Tax revenues levied for the organization's benefit; 5 The value of services or facilities furnished by a governmental unit; 6 Total; 7a Amounts included on lines 1, 2, and 3 received from disqualified persons; 7b Amounts included on lines 2 and 3 received from other than disqualified persons; 8 Public support.

Section B. Total Support

Table with 7 columns: (a) 2020, (b) 2021, (c) 2022, (d) 2023, (e) 2024, (f) Total. Rows include: 9 Amounts from line 6; 10a Gross income from interest, dividends, payments received on securities loans, rents, royalties and income from similar sources; 10b Unrelated business taxable income (less section 511 taxes) from businesses acquired after June 30, 1975; 11 Net income from unrelated business activities not included on line 10b; 12 Other income; 13 Total support; 14 First 5 years.

Section C. Computation of Public Support Percentage

Table with 2 columns: Description, Percentage. Row 15: Public support percentage for 2024; Row 16: Public support percentage from 2023 Schedule A, Part III, line 15.

Section D. Computation of Investment Income Percentage

Table with 2 columns: Description, Percentage. Row 17: Investment income percentage for 2024; Row 18: Investment income percentage from 2023 Schedule A, Part III, line 17; Row 19a: 33 1/3% support tests-2024; Row 19b: 33 1/3% support tests-2023; Row 20: Private foundation.

**Part IV Supporting Organizations**

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

**Section A. All Supporting Organizations**

		Yes	No
<b>1</b>	Are all of the organization's supported organizations listed by name in the organization's governing documents? If "No," describe in <b>Part VI</b> how the supported organizations are designated. If designated by class or purpose, describe the designation. If historic and continuing relationship, explain.		
<b>2</b>	Did the organization have any supported organization that does not have an IRS determination of status under section 509(a)(1) or (2)? If "Yes," explain in <b>Part VI</b> how the organization determined that the supported organization was described in section 509(a)(1) or (2).		
<b>3a</b>	Did the organization have a supported organization described in section 501(c)(4), (5), or (6)? If "Yes," answer lines 3b and 3c below.		
<b>b</b>	Did the organization confirm that each supported organization qualified under section 501(c)(4), (5), or (6) and satisfied the public support tests under section 509(a)(2)? If "Yes," describe in <b>Part VI</b> when and how the organization made the determination.		
<b>c</b>	Did the organization ensure that all support to such organizations was used exclusively for section 170(c)(2)(B) purposes? If "Yes," explain in <b>Part VI</b> what controls the organization put in place to ensure such use.		
<b>4a</b>	Was any supported organization not organized in the United States ("foreign supported organization")? If "Yes" and if you checked box 12a or 12b in Part I, answer lines 4b and 4c below.		
<b>b</b>	Did the organization have ultimate control and discretion in deciding whether to make grants to the foreign supported organization? If "Yes," describe in <b>Part VI</b> how the organization had such control and discretion despite being controlled or supervised by or in connection with its supported organizations.		
<b>c</b>	Did the organization support any foreign supported organization that does not have an IRS determination under sections 501(c)(3) and 509(a)(1) or (2)? If "Yes," explain in <b>Part VI</b> 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.		
<b>5a</b>	Did the organization add, substitute, or remove any supported organizations during the tax year? If "Yes," answer lines 5b and 5c below (if applicable). Also, provide detail in <b>Part VI</b> , 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).		
<b>b</b>	<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?		
<b>c</b>	<b>Substitutions only.</b> Was the substitution the result of an event beyond the organization's control?		
<b>6</b>	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? If "Yes," provide detail in <b>Part VI</b> .		
<b>7</b>	Did the organization provide a grant, loan, compensation, or other similar payment to a substantial contributor (defined in section 4958(c)(3)(C)), a family member of a substantial contributor, or a 35% controlled entity with regard to a substantial contributor? If "Yes," complete Part I of Schedule L (Form 990).		
<b>8</b>	Did the organization make a loan to a disqualified person (as defined in section 4958) not described on line 7? If "Yes," complete Part I of Schedule L (Form 990).		
<b>9a</b>	Was the organization controlled directly or indirectly at any time during the tax year by one or more disqualified persons, as defined in section 4946 (other than foundation managers and organizations described in section 509(a)(1) or (2))? If "Yes," provide detail in <b>Part VI</b> .		
<b>b</b>	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? If "Yes," provide detail in <b>Part VI</b> .		
<b>c</b>	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? If "Yes," provide detail in <b>Part VI</b> .		
<b>10a</b>	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)? If "Yes," answer line 10b below.		
<b>b</b>	Did the organization have any excess business holdings in the tax year? (Use Schedule C, Form 4720, to determine whether the organization had excess business holdings).		

**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>b</b>	A family member of a person described on 11a above?		
<b>c</b>	A 35% controlled entity of a person described on line 11a or 11b above? <i>If "Yes" to 11a, 11b, or 11c, provide detail in Part VI.</i>		

**Section B. Type I Supporting Organizations**

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

**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)? <i>If "No," describe in Part VI how control or management of the supporting organization was vested in the same persons that controlled or managed the supported organization(s).</i>		

**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>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? <i>If "No," explain in Part VI how the organization maintained a close and continuous working relationship with the supported organization(s).</i>		
<b>3</b>	By reason of the relationship described in 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? <i>If "Yes," describe in Part VI the role the organization's supported organizations played in this regard.</i>		

**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 ( <b>see instructions</b> ):		
<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 government entity (see instructions)		
<b>2</b>	Activities Test. <b>Answer lines 2a and 2b below.</b>		
<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? <i>If "Yes," then in Part VI identify those supported organizations and explain how these activities directly furthered their exempt purposes, how the organization was responsive to those supported organizations, and how the organization determined that these activities constituted substantially all of its activities.</i>		
<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? <i>If "Yes," explain in Part VI the reasons for the organization's position that its supported organization(s) would have engaged in these activities but for the organization's involvement.</i>		
<b>3</b>	Parent of Supported Organizations. <b>Answer lines 3a and 3b below.</b>		
<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? <i>If "Yes" or "No", provide details in Part VI.</i>		
<b>b</b>	Did the organization exercise a substantial degree of direction over the policies, programs and activities of each of its supported organizations? <i>If "Yes," describe in Part VI. the role played by the organization in this regard.</i>		

**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.

**Section A - Adjusted Net Income**

(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 Adjusted Net Income</b> (subtract lines 5, 6 and 7 from line 4)  | <b>8</b> |  |  |

**Section B - Minimum Asset Amount**

(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>1</b>  |  |  |
| <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 Total</b> (add lines 1a, 1b, and 1c)  | <b>1d</b> |  |  |
| <b>e 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 Minimum Asset Amount</b> (add line 7 to line 6)   | <b>8</b>  |  |  |

**Section C - Distributable Amount**

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 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 Distributable Amount.</b> Subtract line 5 from line 4, unless subject to emergency temporary reduction (see instructions) | <b>6</b> |  |

- 7**  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 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 2024 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-2024	(iii) Distributable Amount for 2024
<b>1</b> Distributable amount for 2024 from Section C, line 6			
<b>2</b> Underdistributions, if any, for years prior to 2024 (reasonable cause required-- explain in <b>Part VI</b> ). See instructions.			
<b>3</b> Excess distributions carryover, if any, to 2024:			
<b>a</b> From 2019. . . . .			
<b>b</b> From 2020. . . . .			
<b>c</b> From 2021. . . . .			
<b>d</b> From 2022. . . . .			
<b>e</b> From 2023. . . . .			
<b>f Total</b> of lines 3a through e			
<b>g</b> Applied to underdistributions of prior years			
<b>h</b> Applied to 2024 distributable amount			
<b>i</b> Carryover from 2019 not applied (see instructions)			
<b>j</b> Remainder. Subtract lines 3g, 3h, and 3i from line 3f.			
<b>4</b> Distributions for 2024 from Section D, line 7: \$			
<b>a</b> Applied to underdistributions of prior years			
<b>b</b> Applied to 2024 distributable amount			
<b>c</b> Remainder. Subtract lines 4a and 4b from line 4.			
<b>5</b> Remaining underdistributions for years prior to 2024, if any. Subtract lines 3g and 4a from line 2. If the amount is greater than zero, explain in <b>Part VI</b> . See instructions.			
<b>6</b> Remaining underdistributions for 2024. Subtract lines 3h and 4b from line 1. If the amount is greater than zero, explain in <b>Part VI</b> . See instructions.			
<b>7 Excess distributions carryover to 2025.</b> Add lines 3j and 4c.			
<b>8</b> Breakdown of line 7:			
<b>a</b> Excess from 2020. . . . .			
<b>b</b> Excess from 2021. . . . .			
<b>c</b> Excess from 2022. . . . .			
<b>d</b> Excess from 2023. . . . .			
<b>e</b> Excess from 2024. . . . .			

**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).

### Facts And Circumstances Test

Return Reference	Explanation

## Additional Data

[Return to Form](#)

**Software ID:** 24020490

**Software Version:** 2024v5.2

**Schedule of Contributors**

▶ Attach to Form 990, 990-EZ, or 990-PF.  
 ▶ Go to [www.irs.gov/Form990](http://www.irs.gov/Form990) for the latest information.

Name of the organization CONGENITAL HYPERINSULINISM INTERNATIONAL	Employer identification number 20-3068945
--	--

Organization type (check one):

**Filers of:**

**Section:**

- Form 990 or 990-EZ
  - 501(c)( ) (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 other property) from any one contributor. Complete Parts I and II. See instructions for determining a contributor's total contributions.

**Special Rules**

- For an organization described in section 501(c)(3) filing Form 990 or 990-EZ that met the 33<sup>1</sup>/<sub>3</sub>% support test of the regulations under sections 509(a)(1) and 170(b)(1)(A)(vi), that checked Schedule A (Form 990 or 990-EZ), 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, 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, 990-EZ, or 990-PF), 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 990PF, Part I, line 2, to certify that it doesn't meet the filing requirements of Schedule B (Form 990, 990-EZ, or 990-PF).

Name of organization  
 CONGENITAL HYPERINSULINISM INTERNATIONAL

Employer identification number  
 20-3068945

**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
RESTRICTED		\$ RESTRICTED	<input type="checkbox"/> Person <input type="checkbox"/> Payroll <input type="checkbox"/> Noncash (Complete Part II for noncash contributions.)
(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
-		\$	<input type="checkbox"/> Person <input type="checkbox"/> Payroll <input type="checkbox"/> Noncash (Complete Part II for noncash contributions.)
(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
-		\$	<input type="checkbox"/> Person <input type="checkbox"/> Payroll <input type="checkbox"/> Noncash (Complete Part II for noncash contributions.)
(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
-		\$	<input type="checkbox"/> Person <input type="checkbox"/> Payroll <input type="checkbox"/> Noncash (Complete Part II for noncash contributions.)
(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
-		\$	<input type="checkbox"/> Person <input type="checkbox"/> Payroll <input type="checkbox"/> Noncash (Complete Part II for noncash contributions.)
(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
-		\$	<input type="checkbox"/> Person <input type="checkbox"/> Payroll <input type="checkbox"/> Noncash (Complete Part II for noncash contributions.)

Name of organization  
 CONGENITAL HYPERINSULINISM INTERNATIONAL

**Employer identification number**

20-3068945

**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) (See instructions)	(d) Date received
-	_____ _____ _____	_____ \$	_____
(a) No. from Part I	(b) Description of noncash property given	(c) FMV (or estimate) (See instructions)	(d) Date received
-	_____ _____ _____	_____ \$	_____
(a) No. from Part I	(b) Description of noncash property given	(c) FMV (or estimate) (See instructions)	(d) Date received
-	_____ _____ _____	_____ \$	_____
(a) No. from Part I	(b) Description of noncash property given	(c) FMV (or estimate) (See instructions)	(d) Date received
-	_____ _____ _____	_____ \$	_____
(a) No. from Part I	(b) Description of noncash property given	(c) FMV (or estimate) (See instructions)	(d) Date received
-	_____ _____ _____	_____ \$	_____
(a) No. from Part I	(b) Description of noncash property given	(c) FMV (or estimate) (See instructions)	(d) Date received
-	_____ _____ _____	_____ \$	_____

Name of organization  
 CONGENITAL HYPERINSULINISM INTERNATIONAL

Employer identification number  
 20-3068945

**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	
_____		_____	
_____		_____	

## Additional Data

[Return to Form](#)

**Software ID:** 24020490

**Software Version:** 2024v5.2

**SCHEDULE D**  
**(Form 990)**

**Supplemental Financial Statements**

OMB No. 1545-0047

**Open to Public Inspection**

(Rev. January 2025)  
Department of the Treasury  
Internal Revenue Service

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

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

**Name of the organization**  
CONGENITAL HYPERINSULINISM INTERNATIONAL

**Employer identification number**  
20-3068945

**Part I Organizations Maintaining Donor Advised Funds or Other Similar Funds or Accounts.**  
Complete if the organization answered "Yes" on Form 990, Part IV, line 6.

	(a) Donor advised funds	(b) Funds and other accounts
1 Total number at end of year . . . . .		
2 Aggregate value of contributions to (during year)		
3 Aggregate value of grants from (during year)		
4 Aggregate value at end of year . . . . .		

5 Did the organization inform all donors and donor advisors in writing that the assets held in donor advised funds are the organization's property, subject to the organization's exclusive legal control? . . . . .  Yes  No

6 Did the organization inform all grantees, donors, and donor advisors in writing that grant funds can be used only for charitable purposes and not for the benefit of the donor or donor advisor, or for any other purpose conferring impermissible private benefit? . . . . .  Yes  No

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

1 Purpose(s) of conservation easements held by the organization (check all that apply).  
 Preservation of land for public use (e.g., recreation or education)  Preservation of an historically important land area  
 Protection of natural habitat  Preservation of a certified historic structure  
 Preservation of open space

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

	Held at the End of the Year
a Total number of conservation easements . . . . .	2a
b Total acreage restricted by conservation easements . . . . .	2b
c Number of conservation easements on a certified historic structure included in (a) . . . . .	2c
d Number of conservation easements included in (c) acquired after July 25, 2006, and not on a historic structure listed in the National Register . . . . .	2d

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

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

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

6 Staff and volunteer hours devoted to monitoring, inspecting, handling of violations, and enforcing conservation easements during the year  
▶ \_\_\_\_\_

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

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

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

**Part III Organizations Maintaining Collections of Art, Historical Treasures, or Other Similar Assets.**  
Complete if the organization answered "Yes" on Form 990, Part IV, line 8.

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

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

(i) Revenue included on Form 990, Part VIII, line 1 . . . . . ▶ \$ \_\_\_\_\_

(ii) Assets included in Form 990, Part X . . . . . ▶ \$ \_\_\_\_\_

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

a Revenue included on Form 990, Part VIII, line 1 . . . . . ▶ \$ \_\_\_\_\_

b Assets included in Form 990, Part X . . . . . ▶ \$ \_\_\_\_\_

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

- 3 Using the organization's acquisition, accession, and other records, check any of the following that are a significant use of its collection items (check all that apply):
a Public exhibition
b Scholarly research
c Preservation for future generations
d Loan or exchange programs
e Other
4 Provide a description of the organization's collections and explain how they further the organization's exempt purpose in Part XIII.
5 During the year, did the organization solicit or receive donations of art, historical treasures or other similar assets to be sold to raise funds rather than to be maintained as part of the organization's collection? Yes No

Part IV Escrow and Custodial Arrangements.

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

- 1a Is the organization an agent, trustee, custodian or other intermediary for contributions or other assets not included on Form 990, Part X? Yes No
b If "Yes," explain the arrangement in Part XIII and complete the following table:
Table with columns: Amount, 1c Beginning balance, 1d Additions during the year, 1e Distributions during the year, 1f Ending balance
2a Did the organization include an amount on Form 990, Part X, line 21, for escrow or custodial account liability? Yes No
b If "Yes," explain the arrangement in Part XIII. Check here if the explanation has been provided in Part XIII

Part V Endowment Funds.

Complete if the organization answered "Yes" on Form 990, Part IV, line 10.

- Table with columns: (a) Current year, (b) Prior year, (c) Two years back, (d) Three years back, (e) Four years back
1a Beginning of year balance
1b Contributions
1c Net investment earnings, gains, and losses
1d Grants or scholarships
1e Other expenditures for facilities and programs
1f Administrative expenses
1g End of year balance
2 Provide the estimated percentage of the current year end balance (line 1g, column (a)) held as:
a Board designated or quasi-endowment
b Permanent endowment
c Term endowment
The percentages on lines 2a, 2b, and 2c should equal 100%.
3a Are there endowment funds not in the possession of the organization that are held and administered for the organization by:
(i) Unrelated organizations
(ii) Related organizations
b If "Yes" on 3a(ii), are the related organizations listed as required on Schedule R?
4 Describe in Part XIII the intended uses of the organization's endowment funds.

Part VI Land, Buildings, and Equipment.

Complete if the organization answered "Yes" on Form 990, Part IV, line 11a. See Form 990, Part X, line 10.

Table with 4 columns: (a) Cost or other basis (investment), (b) Cost or other basis (other), (c) Accumulated depreciation, (d) Book value
Rows: 1a Land, 1b Buildings, 1c Leasehold improvements, 1d Equipment, 1e Other, Total. Add lines 1a through 1e. (Column (d) must equal Form 990, Part X, column (B), line 10(c).)

**Part VII Investments - Other Securities.**

Complete if the organization answered "Yes" on Form 990, Part IV, line 11b. See Form 990, Part X, line 12.

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

**Part VIII Investments - Program Related.**

Complete if the organization answered 'Yes' on Form 990, Part IV, line 11c. See Form 990, Part X, line 13.

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

**Part IX Other Assets.**

Complete if the organization answered 'Yes' on Form 990, Part IV, line 11d. See Form 990, Part X, line 15.

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

**Part X Other Liabilities.**

Complete if the organization answered 'Yes' on Form 990, Part IV, line 11e or 11f. See Form 990, Part X, line 25.

1. (a) Description of liability	(b) Book value
(1) Federal income taxes	
<b>Total.</b> (Column (b) must equal Form 990, Part X, col.(B) line 25.)	▶

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

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

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

<b>1</b>	Total revenue, gains, and other support per audited financial statements . . . . .		<b>1</b>	1,275,774
<b>2</b>	Amounts included on line 1 but not on Form 990, Part VIII, line 12:			
<b>a</b>	Net unrealized gains (losses) on investments . . . . .	<b>2a</b>		
<b>b</b>	Donated services and use of facilities . . . . .	<b>2b</b>		
<b>c</b>	Recoveries of prior year grants . . . . .	<b>2c</b>		
<b>d</b>	Other (Describe in Part XIII.) . . . . .	<b>2d</b>		
<b>e</b>	Add lines <b>2a</b> through <b>2d</b> . . . . .		<b>2e</b>	
<b>3</b>	Subtract line <b>2e</b> from line <b>1</b> . . . . .		<b>3</b>	1,275,774
<b>4</b>	Amounts included on Form 990, Part VIII, line 12, but not on line 1:			
<b>a</b>	Investment expenses not included on Form 990, Part VIII, line 7b . . . . .	<b>4a</b>		
<b>b</b>	Other (Describe in Part XIII.) . . . . .	<b>4b</b>		
<b>c</b>	Add lines <b>4a</b> and <b>4b</b> . . . . .		<b>4c</b>	
<b>5</b>	Total revenue. Add lines <b>3</b> and <b>4c</b> . (This must equal Form 990, Part I, line 12.) . . . . .		<b>5</b>	1,275,774

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

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

<b>1</b>	Total expenses and losses per audited financial statements . . . . .		<b>1</b>	1,126,855
<b>2</b>	Amounts included on line 1 but not on Form 990, Part IX, line 25:			
<b>a</b>	Donated services and use of facilities . . . . .	<b>2a</b>		
<b>b</b>	Prior year adjustments . . . . .	<b>2b</b>		
<b>c</b>	Other losses . . . . .	<b>2c</b>		
<b>d</b>	Other (Describe in Part XIII.) . . . . .	<b>2d</b>		
<b>e</b>	Add lines <b>2a</b> through <b>2d</b> . . . . .		<b>2e</b>	
<b>3</b>	Subtract line <b>2e</b> from line <b>1</b> . . . . .		<b>3</b>	1,126,855
<b>4</b>	Amounts included on Form 990, Part IX, line 25, but not on line 1:			
<b>a</b>	Investment expenses not included on Form 990, Part VIII, line 7b . . . . .	<b>4a</b>		
<b>b</b>	Other (Describe in Part XIII.) . . . . .	<b>4b</b>		
<b>c</b>	Add lines <b>4a</b> and <b>4b</b> . . . . .		<b>4c</b>	
<b>5</b>	Total expenses. Add lines <b>3</b> and <b>4c</b> . (This must equal Form 990, Part I, line 18.) . . . . .		<b>5</b>	1,126,855

**Part XIII**

**Supplemental Information**

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

Return Reference	Explanation
------------------	-------------

## Additional Data

[Return to Form](#)

**Software ID:** 24020490

**Software Version:** 2024v5.2

**SCHEDULE F  
(Form 990)**  
(Rev. January 2025)

**Statement of Activities Outside the United States**

OMB No. 1545-0047

▶ **Complete if the organization answered "Yes" to Form 990, Part IV, line 14b, 15, or 16.**

▶ **Attach to Form 990.**

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

**Open to Public  
Inspection**

Department of the Treasury  
Internal Revenue Service

Name of the organization  
CONGENITAL HYPERINSULINISM INTERNATIONAL

**Employer identification number**

20-3068945

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

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

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

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

(a) Region	(b) Number of offices in the region	(c) Number of employees, agents, and independent contractors in the region	(d) Activities conducted in region (by type) (such as, fundraising, program services, investments, grants to recipients located in the region)	(e) If activity listed in (d) is a program service, describe specific type of service(s) in the region	(f) Total expenditures for and investments in the region
(1) United Kingdom	0	0	Program	Conference	91,666
(2)					
(3)					
(4)					
(5)					
(6)					
(7)					
(8)					
(9)					
(10)					
(11)					
(12)					
(13)					
(14)					
(15)					
(16)					
(17)					
<b>3a</b> Sub-total . . . . .					91,666
<b>b</b> Total from continuation sheets to Part I . . . . .					
<b>c Totals</b> (add lines 3a and 3b)					91,666

**Part II Grants and Other Assistance to Organizations or Entities Outside the United States.** Complete if the organization answered "Yes" on Form 990, Part IV, line 15, for any recipient who received more than \$5,000. Part II can be duplicated if additional space is needed.

<b>1</b>	<b>(a)</b> Name of organization	<b>(b)</b> IRS code section and EIN (if applicable)	<b>(c)</b> Region	<b>(d)</b> Purpose of grant	<b>(e)</b> Amount of cash grant	<b>(f)</b> Manner of cash disbursement	<b>(g)</b> Amount of noncash assistance	<b>(h)</b> Description of noncash assistance	<b>(i)</b> Method of valuation (book, FMV, appraisal, other)
(1)			United Kingdom	GENETIC TESTING	32,382	Wire			
(2)									
(3)									
(4)									
(5)									
(6)									
(7)									
(8)									
(9)									
(10)									
(11)									
(12)									
(13)									
(14)									
(15)									
(16)									

2 Enter total number of recipient organizations listed above that are recognized as charities by the foreign country, recognized as tax-exempt by the IRS, or for which the grantee or counsel has provided a section 501(c)(3) equivalency letter

3 Enter total number of other organizations or entities 1

**Part III Grants and Other Assistance to Individuals Outside the United States.** Complete if the organization answered "Yes" on Form 990, Part IV, line 16.

Part III can be duplicated if additional space is needed.

<b>(a)</b> Type of grant or assistance	<b>(b)</b> Region	<b>(c)</b> Number of recipients	<b>(d)</b> Amount of cash grant	<b>(e)</b> Manner of cash disbursement	<b>(f)</b> Amount of noncash assistance	<b>(g)</b> Description of noncash assistance	<b>(h)</b> Method of valuation (book, FMV, appraisal, other)
(1)							
(2)							
(3)							
(4)							
(5)							
(6)							
(7)							
(8)							
(9)							
(10)							
(11)							
(12)							
(13)							
(14)							
(15)							
(16)							
(17)							
(18)							

**Part IV Foreign Forms**

- 1 Was the organization a U.S. transferor of property to a foreign corporation during the tax year? *If "Yes," the organization may be required to file Form 926, Return by a U.S. Transferor of Property to a Foreign Corporation (see Instructions for Form 926)* . . . . .  Yes  No
- 2 Did the organization have an interest in a foreign trust during the tax year? *If "Yes," the organization may be required to separately file Form 3520, Annual Return to Report Transactions with Foreign Trusts and Receipt of Certain Foreign Gifts, and/or Form 3520-A, Annual Information Return of Foreign Trust With a U.S. Owner (see Instructions for Forms 3520 and 3520-A; don't file with Form 990)* . . . . .  Yes  No
- 3 Did the organization have an ownership interest in a foreign corporation during the tax year? *If "Yes," the organization may be required to file Form 5471, Information Return of U.S. Persons with Respect to Certain Foreign Corporations. (see Instructions for Form 5471)* . . . . .  Yes  No
- 4 Was the organization a direct or indirect shareholder of a passive foreign investment company or a qualified electing fund during the tax year? *If "Yes," the organization may be required to file Form 8621, Information Return by a Shareholder of a Passive Foreign Investment Company or Qualified Electing Fund. (see Instructions for Form 8621)* .  Yes  No
- 5 Did the organization have an ownership interest in a foreign partnership during the tax year? *If "Yes," the organization may be required to file Form 8865, Return of U.S. Persons with Respect to Certain Foreign Partnerships (see Instructions for Form 8865)* . . . . .  Yes  No
- 6 Did the organization have any operations in or related to any boycotting countries during the tax year? *If "Yes," the organization may be required to separately file Form 5713, International Boycott Report (see Instructions for Form 5713; don't file with Form 990).* . . . . .  Yes  No



## Additional Data

**Software ID:** 24020490

**Software Version:** 2024v5.2

**Supplemental Information Regarding  
 Fundraising or Gaming Activities**

Complete if the organization answered "Yes" on Form 990, Part IV, lines 17, 18, or 19, or if the organization entered more than \$15,000 on Form 990-EZ, line 6a.  
 Attach to Form 990 or Form 990-EZ.  
 Go to [www.irs.gov/Form990](http://www.irs.gov/Form990) for instructions and the latest information.

Name of the organization  
 CONGENITAL HYPERINSULINISM INTERNATIONAL

**Employer identification number**  
 20-3068945

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

- 1** Indicate whether the organization raised funds through any of the following activities. Check all that apply.
- a**  Mail solicitations
  - b**  Internet and email solicitations
  - c**  Phone solicitations
  - d**  In-person solicitations
  - e**  Solicitation of non-government grants
  - f**  Solicitation of government grants
  - g**  Special fundraising events
- 2a** Did the organization have a written or oral agreement with any individual (including officers, directors, trustees or key employees listed in Form 990, Part VII) or entity in connection with professional fundraising services?  Yes  No
- b** If "Yes," list the 10 highest paid individuals or entities (fundraisers) pursuant to agreements under which the fundraiser is to be compensated at least \$5,000 by the organization.

(i) Name and address of individual or entity (fundraiser)	(ii) Activity	(iii) Did fundraiser have custody or control of contributions?		(iv) Gross receipts from activity	(v) Amount paid to (or retained by) fundraiser listed in col. (i)	(vi) Amount paid to (or retained by) organization
		Yes	No			
1						
2						
3						
4						
5						
6						
7						
8						
9						
10						
<b>Total</b>						

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

**Part II Fundraising Events.** Complete if the organization answered "Yes" 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.

Table with 5 columns: Revenue, Direct Expenses, (a) Event #1 (SUGAR SOIREE), (b) Event #2, (c) Other events, (d) Total events. Rows include Gross receipts, Less: Contributions, Gross income, Cash prizes, Noncash prizes, Rent/facility costs, Food and beverages, Entertainment, Other direct expenses, Direct expense summary, and Net income summary.

**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.

Table with 5 columns: Revenue, Direct Expenses, (a) Bingo, (b) Pull tabs/Instant bingo/progressive bingo, (c) Other gaming, (d) Total gaming. Rows include Gross revenue, Cash prizes, Noncash prizes, Rent/facility costs, Other direct expenses, Volunteer labor, Direct expense summary, and Net gaming income summary.

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?
b If "No," explain:
10a Were any of the organization's gaming licenses revoked, suspended or terminated during the tax year?
b If "Yes," explain:

11 Does the organization conduct gaming activities with nonmembers?  Yes  No

12 Is the organization a grantor, beneficiary or trustee of a trust or a member of a partnership or other entity formed to administer charitable gaming?  Yes  No

13 Indicate the percentage of gaming activity conducted in:

a	The organization's facility	13a	%
b	An outside facility	13b	%

14 Enter the name and address of the person who prepares the organization's gaming/special events books and records:

Name ▶ -----

Address ▶ -----

15a Does the organization have a contract with a third party from whom the organization receives gaming revenue?  Yes  No

b If "Yes," enter the amount of gaming revenue received by the organization ▶ \$ \_\_\_\_\_ and the amount of gaming revenue retained by the third party ▶ \$ \_\_\_\_\_.

c If "Yes," enter name and address of the third party:

Name ▶ -----

Address ▶ -----

16 Gaming manager information:

Name ▶ -----

Gaming manager compensation ▶ \$ -----

Description of services provided ▶ -----

Director/officer       Employee       Independent contractor

17 Mandatory distributions:

a Is the organization required under state law to make charitable distributions from the gaming proceeds to retain the state gaming license?  Yes  No

b Enter the amount of distributions required under state law distributed to other exempt organizations or spent in the organization's own exempt activities during the tax year ▶ \$ \_\_\_\_\_

**Part IV Supplemental Information.** Provide the explanations required by Part I, line 2b, columns (iii) and (v); and Part III, lines 9, 9b, 10b, 15b, 15c, 16, and 17b, as applicable. Also provide any additional information. See Instructions.

Return Reference	Explanation
------------------	-------------

**Additional Data**

**Note: To capture the full content of this document, please select landscape mode (11" x 8.5") when printing.**

**Schedule I  
(Form 990)**

(Rev. January 2025)

Department of the Treasury  
Internal Revenue Service

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

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

▶ Attach to Form 990.

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

OMB No. 1545-0047

**Open to Public  
Inspection**

Name of the organization  
CONGENITAL HYPERINSULINISM INTERNATIONAL

Employer identification number  
20-3068945

**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.

(a) Name and address of organization or government	(b) EIN	(c) IRC section (if applicable)	(d) Amount of cash grant	(e) Amount of non-cash assistance	(f) Method of valuation (book, FMV, appraisal, other)	(g) Description of noncash assistance	(h) Purpose of grant or assistance
(1) UNIVERSITY OF PENNSYLVANIA 3535 MARKET STREET PHILIDELPHIA, PA 19104			66,715	0			RESEARCH

**2** Enter total number of section 501(c)(3) and government organizations listed in the line 1 table . . . . . 0

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

**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 noncash assistance	(e) Method of valuation (book, FMV, appraisal, other)	(f) Description of noncash 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.

Return Reference	Explanation
Grantmaker's Description of How Grants are Used	The University of Pennsylvania grant: CHI chose to provide two grants totaling \$66,715 to The University of Pennsylvania Orphan Disease Center Million Dollar Bike Ride Pilot Grant Program (the Program) for congenital hyperinsulinism research. The Program is the only program of its kind to match funds and manage a research grant for congenital hyperinsulinism with guidance from CHI. All individuals holding a faculty-level appointment at an academic institution or a senior scientific position at a non-profit institution or foundation were eligible to respond to this Request for Applications written by CHI. The grant was made available for an innovative, pre-clinical or clinical study that has the potential to lead to: (1) faster and more accurate diagnoses of congenital hyperinsulinism (HI); (2) better HI treatment; (3) a cure for HI; or (4) quality of life improvement for those affected by HI. This grant is made possible by Team Raring to Go for CHI, and CHI and the University of Pennsylvania. CHI recommends grant reviewers for the process which is overseen by The Orphan Disease Center of the University of Pennsylvania.

**Additional Data**

[Return to Form](#)

**Software ID:** 24020490  
**Software Version:** 2024v5.2

**SCHEDULE O**  
**(Form 990)**

(Rev. January 2025)  
Department of the Treasury  
Internal Revenue Service

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

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

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

OMB No. 1545-0047

**Open to Public  
Inspection**

Name of the organization  
CONGENITAL HYPERINSULINISM INTERNATIONAL

**Employer identification number**

20-3068945

<b>Return Reference</b>	<b>Explanation</b>
Form 990, Part VI, Section B, Line 11b	A copy of the Form 990 is provided to the President and Treasurer of the Board of Trustees for review prior to filing and a copy of the Form 990 is provided to the full Board prior to filing.
Form 990, Part VI, Section B, Line 12c	The President of the Board oversees and monitors the adherence to the Conflict of Interest policy. Board members are required to sign and submit the Conflict of Interest policy forms which are reviewed and maintained by the President.
Form 990, Part VI, Section B, Line 15a	The Executive Committee reviews current comparative salaries based on national online resources and makes the salary determination based on performance, experience and longevity with CHI.
Form 990, Part VI, Section C, Line 18	The Form 990 is made available to the public upon request.
Form 990, Part VI, Section C, Line 19	The Form 990 is made available to the public upon request.

## Additional Data

[Return to Form](#)

**Software ID:** 24020490

**Software Version:** 2024v5.2