

990

Return of Organization Exempt From Income Tax

OMB No. 1545-

0047 2022

Open to Public Inspection

Under section 501(c), 527, or 4947(a)(1) of the Internal Revenue Code (except private foundation.) 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 2022 calendar year, or tax year beginning 01-01-2022, and ending 12-31-2022

- 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 \$ 1,316,229

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

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

I Tax-exempt status: 501(c)(3), 501(c) () (insert no.), 4947(a)(1) or 527

J Website: www.congenitalhi.org

K Form of organization: Corporation, Trust, Association, Other

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

Part I Summary

1 Briefly describe the organization's mission or most significant activities: Congenital Hyperinsulinism International's mission is to improve the lives of people with congenital hyperinsulinism, a life-threatening genetic disorder that causes severe hypoglycemia that can lead to seizures, brain damage, or death, if untreated. 2 Check this box if the organization discontinued its operations or disposed of more than 25% of its net assets. 3 Number of voting members of the governing body (Part VI, line 1a) 3 6. 4 Number of independent voting members of the governing body (Part VI, line 1b) 4 6. 5 Total number of individuals employed in calendar year 2022 (Part V, line 2a) 5 5. 6 Total number of volunteers (estimate if necessary) 6 130. 7a Total unrelated business revenue from Part VIII, column (C), line 12 7a 0. 7b Net unrelated business taxable income from Form 990-T, Part I, line 11 7b

Table with columns: Revenue, Expenses, Net Assets or Fund Balances. Rows 8-19. Revenue: 8 Contributions and grants (528,509 / 477,854), 9 Program service revenue (359,850 / 812,623), 10 Investment income (0 / 0), 11 Other revenue (80 / -27,852), 12 Total revenue (888,439 / 1,262,625). Expenses: 13 Grants and similar amounts paid (87,278 / 87,931), 14 Benefits paid to or for members (0 / 0), 15 Salaries, other compensation, employee benefits (343,321 / 395,761), 16a Professional fundraising fees (0 / 0), 16b Total fundraising expenses (94,972 / 94,972), 17 Other expenses (111,229 / 350,363), 18 Total expenses (541,828 / 834,055), 19 Revenue less expenses (346,611 / 428,570). Net Assets or Fund Balances: 20 Total assets (1,177,701 / 1,644,315), 21 Total liabilities (8,582 / 46,626), 22 Net assets or fund balances (1,169,119 / 1,597,689).

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 MASON SMITH Treasurer, Date 2023-11-08

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 EIN 27-2133606, Firm's address 223 LORRAINE AVE MONTCLAIR, NJ 07043, Phone no. (973) 783-2000

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 dedicated to improving the lives of babies, children, and adults affected by congenital hyperinsulinism (HI). CHI provides education, information and support to families of diagnosed children and adults living with the condition. CHI works to promote knowledge and awareness of the disorder as it leads to timely diagnosis and decreases death and brain damage, better care and better neurological outcomes. CHI supports research and development for a better understanding of the condition, leading to a better quality of life, better treatments and management of the condition, and ultimately, a cure.

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 \$ 270,047 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 part of the Million Dollar Bike Ride grant program with the University of Pennsylvania's 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. CHI also administers a one-time hyperinsulinism hyperammonemia (HIHA) pilot grant for an innovative, preclinical study that has the potential to lead to a better HIHA treatment, a cure for HIHA, or improved quality of life to those affected by HIHA. 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. HIGR data is stored on the secure cloud-based IAMRARE platform and hosted by the National Organization for Rare Disorders (NORD). By participating in HIGR, the patient community helps themselves and researchers better understand HI to advance better treatments, a potential cure, and more timely and accurate diagnoses. A new substudy, MAXHIGR, was introduced in 2022 that allows physician reported data to be added to the registry. In 2022, CHI continued developing the Collaborative Research Network, after receiving a Rare As One Grant from the Chan Zuckerberg Initiative to create a prioritized research agenda for 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 seven working groups focused on different aspects of the agenda, comprised of 57 leading researchers, clinicians, and patient advocates from 16 countries. In 2021, CHI continued to support the CHI Centers of Excellence Designation. Six centers were granted the designation and recognized as multi-disciplinary clinical and research centers in the field of congenital hyperinsulinism in 2021. 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 2022, the CHI staff and members of the Board of Trustees were authors of three peer-reviewed publications which meant that the patient voice was included in medical literature for the first time. Global Registries in Congenital Hyperinsulinism, Congenital Hyperinsulinism International: A Community Focused on Improving the Lives of People Living With Congenital Hyperinsulinism, and Congenital hyperinsulinism in infancy and childhood: challenges, unmet needs and the perspective of patients and families were all published in 2022.

4b (Code:) (Expenses \$ 246,407 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, online 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. CHI covers the cost of genetic testing for HI for any patient suspected of having the disease who otherwise cannot afford genetic testing. The testing is conducted by a leading genetics lab at the University of Exeter in the UK.

4c (Code:) (Expenses \$ 187,508 including grants of \$) (Revenue \$)

CHI increases awareness of HI in order to improve timely diagnosis among the public and medical personnel who have a direct opportunity to detect it, 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 24 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 31 family and research meetings and conferences with presentations from academic researchers, members of advocacy organizations, HI patients and families, and biotechnology companies.

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

4e Total program service expenses 703,962

Part IV Checklist of Required Schedules

Table with 3 columns: Question ID, Question Text, and Yes/No response columns. Rows include questions 1 through 21, with sub-questions 11a-e and 12a-b. Each row has a corresponding 'Yes' and 'No' column for the answer.

Part IV Checklist of Required Schedules (continued)

Table with 3 columns: Question ID, Question Text, Yes, No. Rows include questions 22 through 38 regarding tax-exempt bond issues, excess benefit transactions, and related party transactions.

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

Table with 3 columns: Question ID, Question Text, Yes, No. Rows include questions 1a, 1b, and 1c regarding Form 1096, Forms W-2G, and gaming winnings.

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

Table with 17 main rows (2a-17) and sub-rows (a-e). Columns include question text, response boxes (e.g., 2a, 2b, 5, 8, 10a, 10b, 11a, 11b, 12a, 12b, 13a, 13b, 13c, 14a, 14b, 15, 16, 17), and Yes/No/blank response columns.

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 2 columns: Question, Answer. 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 Similar Amounts				
1a Federated campaigns		1a		
b Membership dues		1b		
c Fundraising events		1c	186,539	
d Related organizations		1d		
e Government grants (contributions)		1e		
f All other contributions, gifts, grants, and similar amounts not included above		1f	291,315	
g Noncash contributions included in lines 1a - 1f:\$		1g		
h Total. Add lines 1a-1f				477,854

Program Service Revenue		Business Code		
			(A)	(D)
2a CONFERENCES			143,487	143,487
b RESEARCH			669,136	669,136
c				
d				
e				
f All other program service revenue				
g Total. Add lines 2a-2f.			812,623	

Other Revenue	3 Investment income (including dividends, interest, and other similar amounts)		0			
	4 Income from investment of tax-exempt bond proceeds		0			
	5 Royalties		0			
		(i) Real	(ii) Personal			
	6a Gross rents	6a				
	b Less: rental expenses	6b				
	c Rental income or (loss)	6c				
	d Net rental income or (loss)			0		
		(i) Securities	(ii) Other			
	7a Gross amount from sales of assets other than inventory	7a				
	b Less: cost or other basis and sales expenses	7b				
	c Gain or (loss)	7c				
	d Net gain or (loss)			0		
	8a Gross income from fundraising events (not including \$ 186,539 of contributions reported on line 1c). See Part IV, line 18	8a	23,750			
	b Less: direct expenses	8b	53,604			
c Net income or (loss) from fundraising events			-29,854			
9a Gross income from gaming activities. See Part IV, line 19	9a					
b Less: direct expenses	9b					
c Net income or (loss) from gaming activities			0			
10a Gross sales of inventory, less returns and allowances	10a					
b Less: cost of goods sold	10b					
c Net income or (loss) from sales of inventory			0			

Other Revenue Misc Amt		Business Code		
			(A)	(C)
11a Misc revenue		900099	2,002	2,002
b				
c				
d All other revenue				
e Total. Add lines 11a-11d			2,002	
12 Total revenue. See instructions			1,262,625	2,002

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

Table with 5 columns: (A) Total expenses, (B) Program service expenses, (C) Management and general expenses, (D) Fundraising expenses. Rows include categories like Grants, Salaries, Payroll taxes, and Total functional expenses.

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
Assets	1 Cash-non-interest-bearing	1,093,945	1	1,510,108
	2 Savings and temporary cash investments		2	0
	3 Pledges and grants receivable, net	79,802	3	116,060
	4 Accounts receivable, net		4	0
	5 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		5	0
	6 Loans and other receivables from other disqualified persons (as defined under section 4958(f)(1)), and persons described in section 4958(c)(3)(B)		6	0
	7 Notes and loans receivable, net		7	0
	8 Inventories for sale or use		8	0
	9 Prepaid expenses and deferred charges	3,954	9	18,147
	10a Land, buildings, and equipment: cost or other basis. Complete Part VI of Schedule D 10a			
	b Less: accumulated depreciation 10b		10c	0
	11 Investments—publicly traded securities		11	0
	12 Investments—other securities. See Part IV, line 11		12	0
	13 Investments—program-related. See Part IV, line 11		13	0
	14 Intangible assets		14	0
	15 Other assets. See Part IV, line 11		15	0
16 Total assets: Add lines 1 through 15 (must equal line 33)	1,177,701	16	1,644,315	
Liabilities	17 Accounts payable and accrued expenses	8,582	17	46,626
	18 Grants payable		18	
	19 Deferred revenue		19	
	20 Tax-exempt bond liabilities		20	
	21 Escrow or custodial account liability. Complete Part IV of Schedule D		21	
	22 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		22	
	23 Secured mortgages and notes payable to unrelated third parties		23	
	24 Unsecured notes and loans payable to unrelated third parties		24	
	25 Other liabilities (including federal income tax, payables to related third parties, and other liabilities not included on lines 17 - 24). Complete Part X of Schedule D		25	
	26 Total liabilities. Add lines 17 through 25	8,582	26	46,626
Net Assets or Fund Balances	Organizations that follow FASB ASC 958, check here <input checked="" type="checkbox"/> and complete lines 27, 28, 32, and 33.			
	27 Net assets without donor restrictions	1,134,119	27	1,562,689
	28 Net assets with donor restrictions	35,000	28	35,000
	Organizations that do not follow FASB ASC 958, check here <input type="checkbox"/> and complete lines 29 through 33.			
	29 Capital stock or trust principal, or current funds		29	
	30 Paid-in or capital surplus, or land, building or equipment fund		30	
	31 Retained earnings, endowment, accumulated income, or other funds		31	
	32 Total net assets or fund balances	1,169,119	32	1,597,689
33 Total liabilities and net assets/fund balances	1,177,701	33	1,644,315	

Part XI Reconciliation of Net Assets

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

1	Total revenue (must equal Part VIII, column (A), line 12)	1	1,262,625
2	Total expenses (must equal Part IX, column (A), line 25)	2	834,055
3	Revenue less expenses. Subtract line 2 from line 1	3	428,570
4	Net assets or fund balances at beginning of year (must equal Part X, line 32, column (A))	4	1,169,119
5	Net unrealized gains (losses) on investments	5	
6	Donated services and use of facilities	6	
7	Investment expenses	7	
8	Prior period adjustments	8	
9	Other changes in net assets or fund balances (explain in Schedule O)	9	
10	Net assets or fund balances at end of year. Combine lines 3 through 9 (must equal Part X, line 32, column (A))	10	1,597,689

Part XII Financial Statements and Reporting

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

		Yes	No
1	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.		
2a	Were the organization's financial statements compiled or reviewed by an independent accountant? If 'Yes,' check a box below to indicate whether the financial statements for the year were compiled or reviewed on a separate basis, consolidated basis, or both: <input type="checkbox"/> Separate basis <input type="checkbox"/> Consolidated basis <input type="checkbox"/> Both consolidated and separate basis		No
2b	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	
2c	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	
3a	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
3b	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: 22015553

Software Version: 2022v5.0

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 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		
Total						

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

Table with 7 columns: (a) 2018, (b) 2019, (c) 2020, (d) 2021, (e) 2022, (f) Total. Rows include: 1 Gifts, grants, contributions, and membership fees received; 2 Tax revenues levied for the organization's benefit; 3 Value of services or facilities; 4 Total; 5 Portion of total contributions exceeding 2%; 6 Public support.

Section B. Total Support

Table with 7 columns: (a) 2018, (b) 2019, (c) 2020, (d) 2021, (e) 2022, (f) Total. Rows include: 7 Amounts from line 4; 8 Gross income from interest, dividends, payments received on securities loans, rents, royalties and income from similar sources; 9 Net income from unrelated business activities; 10 Other income; 11 Total support; 12 Gross receipts from related activities; 13 First 5 years.

Section C. Computation of Public Support Percentage

Table with 2 columns: Line number, Percentage. Rows include: 14 Public support percentage for 2022; 15 Public support percentage for 2020; 16a 33 1/3% support test-2022; b 33 1/3% support test-2021; 17a 10%-facts-and-circumstances test-2022; b 10%-facts-and-circumstances test-2021; 18 Private foundation.

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) 2018, (b) 2019, (c) 2020, (d) 2021, (e) 2022, (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) 2018, (b) 2019, (c) 2020, (d) 2021, (e) 2022, (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; 10c Add lines 10a and 10b; 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 2022 (line 8, column (f) divided by line 13, column (f)). Row 16: Public support percentage from 2021 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 2022 (line 10c, column (f) divided by line 13, column (f)). Row 18: Investment income percentage from 2021 Schedule A, Part III, line 17.

- 19a 33 1/3% support tests-2022. If the organization did not check the box on line 14, and line 15 is more than 33 1/3%, and line 17 is not more than 33 1/3%, check this box and stop here.
b 33 1/3% support tests-2021. If the organization did not check a box on line 14 or line 19a, and line 16 is more than 33 1/3% and line 18 is not more than 33 1/3%, check this box and stop here.
20 Private foundation. If the organization did not check a box on line 14, 19a, or 19b, check this box and see instructions.

Part IV Supporting Organizations

(Complete only if you checked a box on line 12 of Part I. If you checked box 12a, 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
1	Are all of the organization's supported organizations listed by name in the organization's governing documents? If "No," describe in Part VI how the supported organizations are designated. If designated by class or purpose, describe the designation. If historic and continuing relationship, explain.		
2	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 Part VI how the organization determined that the supported organization was described in section 509(a)(1) or (2).		
3a	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	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 Part VI when and how the organization made the determination.		
c	Did the organization ensure that all support to such organizations was used exclusively for section 170(c)(2)(B) purposes? If "Yes," explain in Part VI what controls the organization put in place to ensure such use.		
4a	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	Did the organization have ultimate control and discretion in deciding whether to make grants to the foreign supported organization? If "Yes," describe in Part VI how the organization had such control and discretion despite being controlled or supervised by or in connection with its supported organizations.		
c	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 Part VI what controls the organization used to ensure that all support to the foreign supported organization was used exclusively for section 170(c)(2)(B) purposes.		
5a	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 Part VI , including (i) the names and EIN numbers of the supported organizations added, substituted, or removed; (ii) the reasons for each such action; (iii) the authority under the organization's organizing document authorizing such action; and (iv) how the action was accomplished (such as by amendment to the organizing document).		
b	Type I or Type II only. Was any added or substituted supported organization part of a class already designated in the organization's organizing document?		
c	Substitutions only. Was the substitution the result of an event beyond the organization's control?		
6	Did the organization provide support (whether in the form of grants or the provision of services or facilities) to anyone other than (i) its supported organizations, (ii) individuals that are part of the charitable class benefited by one or more of its supported organizations, or (iii) other supporting organizations that also support or benefit one or more of the filing organization's supported organizations? If "Yes," provide detail in Part VI .		
7	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).		
8	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).		
9a	Was the organization controlled directly or indirectly at any time during the tax year by one or more disqualified persons, as defined in section 4946 (other than foundation managers and organizations described in section 509(a)(1) or (2))? If "Yes," provide detail in Part VI .		
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 Part VI .		
c	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 Part VI .		
10a	Was the organization subject to the excess business holdings rules of section 4943 because of section 4943(f) (regarding certain Type II supporting organizations, and all Type III non-functionally integrated supporting organizations)? If "Yes," answer line 10b below.		
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
11 Has the organization accepted a gift or contribution from any of the following persons?		
a 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 A family member of a person described on 11a above?		
c 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
1 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>		
2 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
1 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
1 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?		
2 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>		
3 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

1 Check the box next to the method that the organization used to satisfy the Integral Part Test during the year (see instructions):

- a** The organization satisfied the Activities Test. Complete **line 2** below.
- b** The organization is the parent of each of its supported organizations. Complete **line 3** below.
- c** The organization supported a governmental entity. Describe in **Part VI** how you supported a government entity (see instructions)

2 Activities Test. **Answer lines 2a and 2b below.**

	Yes	No
a 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 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>		

3 Parent of Supported Organizations. **Answer lines 3a and 3b below.**

	Yes	No
a 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 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)

- | | | | |
|---|----------|--|--|
| 1 Net short-term capital gain | 1 | | |
| 2 Recoveries of prior-year distributions | 2 | | |
| 3 Other gross income (see instructions) | 3 | | |
| 4 Add lines 1 through 3 | 4 | | |
| 5 Depreciation and depletion | 5 | | |
| 6 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) | 6 | | |
| 7 Other expenses (see instructions) | 7 | | |
| 8 Adjusted Net Income (subtract lines 5, 6 and 7 from line 4) | 8 | | |

Section B - Minimum Asset Amount

(A) Prior Year

(B) Current Year
(optional)

- | | | | |
|--|-----------|--|--|
| 1 Aggregate fair market value of all non-exempt-use assets (see instructions for short tax year or assets held for part of year): | 1 | | |
| a Average monthly value of securities | 1a | | |
| b Average monthly cash balances | 1b | | |
| c Fair market value of other non-exempt-use assets | 1c | | |
| d Total (add lines 1a, 1b, and 1c) | 1d | | |
| e Discount claimed for blockage or other factors (<i>explain in detail in Part VI</i>): | | | |
| 2 Acquisition indebtedness applicable to non-exempt use assets | 2 | | |
| 3 Subtract line 2 from line 1d | 3 | | |
| 4 Cash deemed held for exempt use. Enter 0.015 of line 3 (for greater amount, see instructions). | 4 | | |
| 5 Net value of non-exempt-use assets (subtract line 4 from line 3) | 5 | | |
| 6 Multiply line 5 by 0.035 | 6 | | |
| 7 Recoveries of prior-year distributions | 7 | | |
| 8 Minimum Asset Amount (add line 7 to line 6) | 8 | | |

Section C - Distributable Amount

Current Year

- | | | |
|--|----------|--|
| 1 Adjusted net income for prior year (from Section A, line 8, Column A) | 1 | |
| 2 Enter 85% of line 1 | 2 | |
| 3 Minimum asset amount for prior year (from Section B, line 8, Column A) | 3 | |
| 4 Enter greater of line 2 or line 3 | 4 | |
| 5 Income tax imposed in prior year | 5 | |
| 6 Distributable Amount. Subtract line 5 from line 4, unless subject to emergency temporary reduction (see instructions) | 6 | |

- 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
1 Amounts paid to supported organizations to accomplish exempt purposes	1	
2 Amounts paid to perform activity that directly furthers exempt purposes of supported organizations, in excess of income from activity	2	
3 Administrative expenses paid to accomplish exempt purposes of supported organizations	3	
4 Amounts paid to acquire exempt-use assets	4	
5 Qualified set-aside amounts (<i>prior IRS approval required - provide details in Part VI</i>)	5	
6 Other distributions (<i>describe in Part VI</i>). See instructions	6	
7 Total annual distributions. Add lines 1 through 6.	7	
8 Distributions to attentive supported organizations to which the organization is responsive (<i>provide details in Part VI</i>). See instructions	8	
9 Distributable amount for 2022 from Section C, line 6	9	
10 Line 8 amount divided by Line 9 amount	10	

Section E - Distribution Allocations (see instructions)	(i) Excess Distributions	(ii) Underdistributions Pre-2022	(iii) Distributable Amount for 2022
1 Distributable amount for 2022 from Section C, line 6			
2 Underdistributions, if any, for years prior to 2022 (<i>reasonable cause required-- explain in Part VI</i>). See instructions.			
3 Excess distributions carryover, if any, to 2022:			
a From 2017.			
b From 2018.			
c From 2019.			
d From 2020.			
e From 2021.			
f Total of lines 3a through e			
g Applied to underdistributions of prior years			
h Applied to 2022 distributable amount			
i Carryover from 2017 not applied (see instructions)			
j Remainder. Subtract lines 3g, 3h, and 3i from line 3f.			
4 Distributions for 2022 from Section D, line 7: \$			
a Applied to underdistributions of prior years			
b Applied to 2022 distributable amount			
c Remainder. Subtract lines 4a and 4b from line 4.			
5 Remaining underdistributions for years prior to 2022, if any. Subtract lines 3g and 4a from line 2. If the amount is greater than zero, <i>explain in Part VI</i> . See instructions.			
6 Remaining underdistributions for 2022. Subtract lines 3h and 4b from line 1. If the amount is greater than zero, <i>explain in Part VI</i> . See instructions.			
7 Excess distributions carryover to 2023. Add lines 3j and 4c.			
8 Breakdown of line 7:			
a Excess from 2018.			
b Excess from 2019.			
c Excess from 2020.			
d Excess from 2021.			
e Excess from 2022.			

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

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Schedule B

Schedule of Contributors

OMB No. 1545-0047

(Form 990)
Department of the Treasury
Internal Revenue Service

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

2022

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 33¹/₃% 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.)
-		\$	<input type="checkbox"/> Person <input type="checkbox"/> Payroll <input type="checkbox"/> Noncash (Complete Part II for noncash contributions.)
-		\$	<input type="checkbox"/> Person <input type="checkbox"/> Payroll <input type="checkbox"/> Noncash (Complete Part II for noncash contributions.)
-		\$	<input type="checkbox"/> Person <input type="checkbox"/> Payroll <input type="checkbox"/> Noncash (Complete Part II for noncash contributions.)
-		\$	<input type="checkbox"/> Person <input type="checkbox"/> Payroll <input type="checkbox"/> Noncash (Complete Part II for noncash contributions.)
-		\$	<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
-	_____ _____ _____	_____ \$	_____
-	_____ _____ _____	_____ \$	_____
-	_____ _____ _____	_____ \$	_____
-	_____ _____ _____	_____ \$	_____
-	_____ _____ _____	_____ \$	_____
-	_____ _____ _____	_____ \$	_____
-	_____ _____ _____	_____ \$	_____
-	_____ _____ _____	_____ \$	_____
-	_____ _____ _____	_____ \$	_____
-	_____ _____ _____	_____ \$	_____

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

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Supplemental Financial Statements

2022

Open to Public Inspection

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 for instructions and the latest information.

Department of the Treasury Internal Revenue Service

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.

Table with 2 columns: (a) Donor advised funds, (b) Funds and other accounts. Rows include total number at end of year, aggregate value of contributions, grants, and end of year, and two yes/no questions about donor informed.

Part II Conservation Easements.

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

Form for Part II Conservation Easements. Includes checkboxes for types of easements, a table for 'Held at the End of the Year' (2a-2d), and questions about monitoring, expenses, and reporting.

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.

Form for Part III Organizations Maintaining Collections of Art, Historical Treasures, or Other Similar Assets. Includes questions about reporting art collections and amounts received or held.

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:

	Amount
c Beginning balance	1c
d Additions during the year	1d
e Distributions during the year	1e
f Ending balance	1f

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.

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

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

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

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

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

Part VI Land, Buildings, and Equipment.

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

Description of property	(a) Cost or other basis (investment)	(b) Cost or other basis (other)	(c) Accumulated depreciation	(d) Book value
1a Land				
b Buildings				
c Leasehold improvements				
d Equipment				
e Other				

Total. Add lines 1a 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)		
Total. (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)		
Total. (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)	
Total. (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	
(2)	
(3)	
(4)	
(5)	
(6)	
(7)	
(8)	
(9)	
Total. (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.

1	Total revenue, gains, and other support per audited financial statements		1	1,265,639
2	Amounts included on line 1 but not on Form 990, Part VIII, line 12:			
a	Net unrealized gains (losses) on investments	2a		
b	Donated services and use of facilities	2b	3,014	
c	Recoveries of prior year grants	2c		
d	Other (Describe in Part XIII.)	2d		
e	Add lines 2a through 2d		2e	3,014
3	Subtract line 2e from line 1		3	1,262,625
4	Amounts included on Form 990, Part VIII, line 12, but not on line 1:			
a	Investment expenses not included on Form 990, Part VIII, line 7b	4a		
b	Other (Describe in Part XIII.)	4b		
c	Add lines 4a and 4b		4c	
5	Total revenue. Add lines 3 and 4c . (This must equal Form 990, Part I, line 12.)		5	1,262,625

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.

1	Total expenses and losses per audited financial statements		1	837,069
2	Amounts included on line 1 but not on Form 990, Part IX, line 25:			
a	Donated services and use of facilities	2a	3,014	
b	Prior year adjustments	2b		
c	Other losses	2c		
d	Other (Describe in Part XIII.)	2d		
e	Add lines 2a through 2d		2e	3,014
3	Subtract line 2e from line 1		3	834,055
4	Amounts included on Form 990, Part IX, line 25, but not on line 1:			
a	Investment expenses not included on Form 990, Part VIII, line 7b	4a		
b	Other (Describe in Part XIII.)	4b		
c	Add lines 4a and 4b		4c	
5	Total expenses. Add lines 3 and 4c . (This must equal Form 990, Part I, line 18.)		5	834,055

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
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Additional Data

[Return to Form](#)

Software ID: 22015553

Software Version: 2022v5.0

**SCHEDULE F
(Form 990)**

Statement of Activities Outside the United States

OMB No. 1545-0047

2022

**Open to Public
Inspection**

▶ **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 for instructions and the latest information.**

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 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)					
(2)					
(3)					
(4)					
(5)					
(6)					
(7)					
(8)					
(9)					
(10)					
(11)					
(12)					
(13)					
(14)					
(15)					
(16)					
(17)					
3a Sub-total					
b Total from continuation sheets to Part I					
c Totals (add lines 3a and 3b)					

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.

1	(a) Name of organization	(b) IRS code section and EIN (if applicable)	(c) Region	(d) Purpose of grant	(e) Amount of cash grant	(f) Manner of cash disbursement	(g) Amount of noncash assistance	(h) Description of noncash assistance	(i) Method of valuation (book, FMV, appraisal, other)
(1)			UK	GENETIC TESTING	25,546	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.

(a) Type of grant or assistance	(b) Region	(c) Number of recipients	(d) Amount of cash grant	(e) Manner of cash disbursement	(f) Amount of noncash assistance	(g) Description of noncash assistance	(h) 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

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**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 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 <input type="checkbox"/> Mail solicitations | e <input type="checkbox"/> Solicitation of non-government grants |
| b <input type="checkbox"/> Internet and email solicitations | f <input type="checkbox"/> Solicitation of government grants |
| c <input type="checkbox"/> Phone solicitations | g <input type="checkbox"/> Special fundraising events |
| d <input type="checkbox"/> In-person solicitations | |
- 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						
Total						

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

.....

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

		(a)Event #1 SUGAR SOIREE (event type)	(b) Event #2 (event type)	(c)Other events (total number)	(d) Total events (add col. (a) through col. (c))
Revenue	1 Gross receipts	210,289			210,289
	2 Less: Contributions	186,539			186,539
	3 Gross income (line 1 minus line 2)	23,750			23,750
Direct Expenses	4 Cash prizes				
	5 Noncash prizes				
	6 Rent/facility costs	50,303			50,303
	7 Food and beverages				
	8 Entertainment				
	9 Other direct expenses	3,301			3,301
	10 Direct expense summary. Add lines 4 through 9 in column (d) ▶				53,604
11 Net income summary. Subtract line 10 from line 3, column (d) ▶				-29,854	

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

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

9 Enter the state(s) in which the organization conducts gaming activities: _____

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

b If "No," explain: _____

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

b If "Yes," explain: _____

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

**Schedule I
(Form 990)**

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

OMB No. 1545-0047

2022

**Open to Public
Inspection**

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 for the latest information.

Department of the
Treasury
Internal Revenue Service

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, P A 19104			40,000	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 a grant in the amount of \$40,000 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

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SCHEDULE O
(Form 990)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 for the latest information.**

OMB No. 1545-0047

2022**Open to Public
Inspection**Name of the organization
CONGENITAL HYPERINSULINISM INTERNATIONAL**Employer identification number**

20-3068945

Return Reference	Explanation
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

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