ECD GLOBAL ALLIANCE INC

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ECD GLOBAL ALLIANCE INC

aka Erdheim-Chester Disease Global Alliance

- Oeridder, LA
- http://erdheim-chester.org/
- (337)515-6987



View GuideStar Profile

MISSION

The ECD Global Alliance is dedicated to the awareness, support, education, and research related to Erdheim-Chester Disease. Towards this mission, the organization will work with the global community to: (1) To facilitate early diagnosis of the disease (2) To lessen the burden as much as possible to those affected by ECD. (3) To learn more about (a) the disease, (b) effective treatments for the disease, (c) possible cures, and/or (d) avenues to prevent the disease altogether. (4) Provide current, reliable, and factual information related to ECD to patients, loved ones, medical personnel, research personnel, media, and other organizations. It will also include promoting, sponsoring and conducting workshops, symposiums and other meetings to promote the goals of the alliance.

EIN

27-0759192

RULING YEAR

2010

IRS SUBSECTION

501(c)(3) Public Charity

MAIN ADDRESS

715 Davella Dr Deridder, LA 70634-4731

AFFILIATION TYPE

Independent Organization

CONTACT

Kathy Brewer, President (337) 515-6987 support@erdheim-chester.org

Transparency 2025 Candid

Platinum

PRESIDENT

Kathy Brewer

BOARD CHAIR

Kathy Brewer

SUBJECT AREA

Diseases and conditions

NTEE Code

Specifically Named Diseases (G80)

PROGRAMS

1. ECD Global Alliance Grants

Population(s) served:

2. Grants to Individuals Program

Population(s) served:

3. Support to those Affected by ECD

Population(s) served: People with diseases and illnesses, Caregivers

4. Support Erdheim-Chester Disease Research

Population(s) served: People with diseases and illnesses, Caregivers

5. Raise Awareness of ECD and Provide Public ECD Information

Population(s) served: Adults

POPULATIONS SERVED

- 1. People with diseases and illnesses
- 2. Caregivers
- 3. Adults

COMPLIANCE

- ✓ IRS Pub 78 Verified as of November 2025
- ✓ IRS BMF 509(a) (1) as of November 14, 2025
- X A-133 Audit Required/Performed?
- ✓ Conflict of Interest Policy
- ✓ Written whistleblower policy

Section 509(a)(1) organization as referred to in Section 170(b)(1)(A)(vi)

TRANSPARENCY MEASURES

- X Board Practices Reported?
- ✓ Diversity Data Reported?
- 8 Number of Independent Board Members

Programs & Results

PROGRAMS

GUIDESTAR PRO REPORT

Source: Self-Reported by Organization, March 2025

ECD Global Alliance Grants

Population(s) Served: n/a

Grant are provided in amounts up to \$50,000 per year to principal investigators who hold post-doctoral positions or beyond. Projects will ordinarily be funded for one year, where appropriate, funding requests for follow on study is encouraged. Proposed projects must have specific relevance to ECD, and show promise for contributing to the scientific advancement in this field of study

Grants to Individuals Program

Population(s) Served: n/a

Grants to investigators who seek to conduct research to find the cause, treatment or cure for Erdheim Chester Disease (ECD)

Support to those Affected by ECD

Population(s) Served: n/a

Erdheim-Chester Disease is so rare that most medical professionals have never heard of it. The ECD Global Alliance has created and supports an ECD Referral Care Center Network that allows patients to be seen at institutions committed to the care of ECD patients by knowledgeable medical professionals. The ECD Global Alliance also offers patients and caregivers access to others from around the world through the support of online chat sessions, social media, and annual international Patient & Family Gatherings.

Support Erdheim-Chester Disease Research

Population(s) Served: n/a

Raise funds to support research to learn more about ECD in an effort to find more effective, targeted and rational treatments. Connect members with medical professionals, available trials, and updated information.

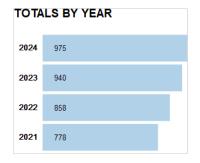
Raise Awareness of ECD and Provide Public ECD Information

Population(s) Served: n/a

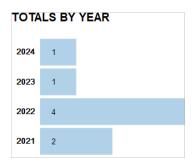
The ECD Global Alliance provides a website – (http://erdheim-chester.org) and various social media outlets dedicated to providing the most up-to-date information about Erdheim-Chester Disease. As well as hosting various awareness events throughout the year. The ECD Awareness week event is hosted every year during the second week in September.

RESULTS

Number of clients served



Number of research studies funded



Population(s) Served: No target populations selected

Related program: Support to those Affected by

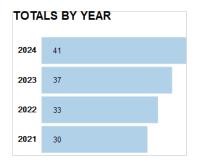
Notes: This metric tracks the number of patients the ECD has serviced.

Population(s) Served: No target populations selected

Related program: Support Erdheim-Chester Disease Research

Notes: The ECDGA tracks the number and dollar amount of research projects that the organization funds.

Number of clinic sites



Population(s) Served: No target populations selected

Related program: Support to those Affected by ECD

Notes: This is the number of ECD Referral Care Centers identified and supported.

CHARTING IMPACT

What is the organization aiming to accomplish?

Awareness & Education. Educate more medical personnel to dramatically improve the timeliness of ECD diagnoses.

Patient Support. Empower and strengthen a community of informed and connected patients, caregivers, and physicians.

Research Program. Enhance collaborative research with a patient-centered approach.

Sustainability. Establish long-term stability for the ECD Global Alliance so that it can continue serving the community for decades to come.

What are the organization's key strategies for making this happen?

We will be present at 3-4 medical specialty conferences annually to bring ECD to the attention of specialists who may encounter the disease and be in a position to diagnose the disease early in the progression.

Provide patient and caregiver networking opportunities to bring together patients and caregivers virtually.

Provide Patient Navigation services to help community members find the answers they need.

Host webinars, sharing information with patients, caregivers, family members, and medical professionals.

Host an international, annual conference for patients, family members, medical professionals, and scientists to facilitate collaboration and ensure the community works together to meet patient and family needs.

Launch research studies through an annual grant program.

Financials

FISCAL YEAR START: 01/01 FISCAL YEAR END: 12/31

FINANCIALS QUICK VIEW

Surpluses in last 5 years 4

Negative Net Assets in past 5 years 0

Financial Trends Analysis

Business Model Indicators





Profitability	2019	2020	2021	2022	2023
Unrestricted surplus (deficit) before depreciation	\$46,596	\$115,124	\$180,662	\$596,541	-\$486,764
As a % of expenses	17.6%	98.9%	147.6%	291.3%	-87.8%
Unrestricted surplus (deficit) after depreciation	\$46,596	\$115,124	\$180,662	\$596,541	-\$486,764
As a % of expenses	17.6%	98.9%	147.6%	291.3%	-87.8%
Revenue Composition					
Total revenue (unrestricted & restricted)	\$311,104	\$238,125	\$303,089	\$801,337	\$417,616
Total revenue, % change over prior year	19.8%	-23.5%	27.3%	164.4%	-47.9%
Program services revenue	0.0%	0.0%	0.0%	0.0%	0.0%
Membership dues	0.0%	0.0%	0.0%	0.0%	0.0%
Investment income	9.9%	0.0%	8.1%	-3.0%	9.9%
Government grants	0.0%	2.1%	0.0%	0.0%	0.0%
All other grants and contributions	90.1%	97.9%	91.9%	103.0%	90.1%
Other revenue	0.0%	0.0%	0.0%	0.0%	0.0%
Expense Composition					
Total expenses before depreciation	\$264,508	\$116,443	\$122,427	\$204,796	\$554,648
Total expenses, % change over prior year	107.2%	-56.0%	5.1%	67.3%	170.8%
Personnel	24.1%	44.5%	45.3%	50.4%	20.3%
Professional Fees	0.0%	4.3%	31.4%	3.5%	18.7%
Occupancy	0.0%	0.0%	0.0%	0.0%	0.0%
Interest	0.0%	0.0%	0.0%	0.0%	0.0%
Pass-Through	41.8%	32.2%	0.4%	26.0%	44.6%
All other expenses	34.2%	19.0%	22.9%	20.2%	16.3%

Financial Trends Analysis, continued

Moving Toward Full Cost Coverage

Full Cost Components (estimated)	2019	2020	2021	2022	2023
Total Expenses (after depreciation)	\$264,508	\$116,443	\$122,427	\$204,796	\$554,648
One Month of Savings	\$22,042	\$9,704	\$10,202	\$17,066	\$46,221
Debt Principal Repayment	\$0	\$0	\$0	\$0	\$0
Fixed Asset Additions	\$0	\$0	\$0	\$0	\$0
Total Full Costs (estimated)	\$286,550	\$126,147	\$132,629	\$221,862	\$600,869

Capital Structure Indicators

Liquidity					
Months of cash	21.6	61.8	74.1	51.3	15.1
Months of cash and investments	28.4	76.4	90.5	89.1	29.9
Months of estimated liquid unrestricted net assets	28.4	76.3	90.3	88.9	22.3
Balance Sheet Composition					
Cash	\$475,825	\$599,346	\$756,469	\$876,074	\$696,211
Investments	\$149,556	\$142,060	\$166,474	\$645,157	\$684,188
Receivables	\$0	\$0	\$0	\$0	\$5,520
Gross land, buildings, and equipment (LBE)	\$0	\$0	\$0	\$0	\$0
Accumulated depreciation (% of LBE)	0.0%	0.0%	0.0%	0.0%	0.0%
Liabilities (as % of assets)	0.0%	0.1%	0.2%	0.2%	0.4%
Unrestricted net assets	\$0	\$0	\$0	\$0	\$1,030,834
Temporarily restricted net assets	N/A	N/A	N/A	N/A	N/A
Permanently restricted net assets	N/A	N/A	N/A	N/A	N/A
Total restricted net assets	\$0	\$0	\$0	\$0	\$349,732
Total net assets	\$625,271	\$740,395	\$921,057	\$1,517,598	\$1,380,566

Key Data Checks

Material Data Errors	2019	2020	2021	2022	2023
	No	No	No	No	No

Note: This issue is relevant to a small number of organizations: The nonprofit subject(s) of this report may have affiliates. The Form 990 data may not include information about any or all potential affiliates. If an organization does have affiliates and these affiliates have substantial financial activity, the financial data in this report may not present a comprehensive picture of the nonprofit's financial condition. Please consult the 990s of any potentially related affiliates for additional information.

- ☑ <u>'Key Revenue & Expense Data from Form 990'</u>
- 'Key Balance Sheet Data from Form 990'

Operations

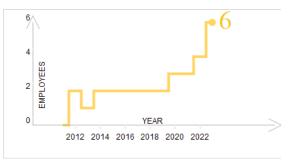
Source: Self-Reported by Organization, March 2025

PRESIDENT

Kathy Brewer

NUMBER OF EMPLOYEES

Source: IRS Form 990



BOARD CHAIR

Kathy Brewer

No Affiliation

BOARD MEMBERS

David Smythe

David Smythe

Diane Schriner

Janet Froetscher

Janet Froetscher

Joe Fleischhacker

Joe Fleischhaker

Juvi Veras

Juvianee Estrada-Veras

Kathleen Brewer

Kathy Brewer

No Affiliation

Mohammad Chowdhury

Paul Hendrie

Paul Hendrie

Name	Title	Compensation	Other	Related
Janet Froetscher	SECRETARY	\$0	\$0	\$0
Paul Hendrie	DIRECTOR	\$0	\$0	\$0
Joe Fleischhaker	DIRECTOR	\$0	\$0	\$0
David Smythe	DIRECTOR	\$0	\$0	\$0
Juvi Estrada Veras	DIRECTOR	\$0	\$0	\$0
Kathy Brewer	PRESIDENT	\$0	\$0	\$0
Diane Schriner	VICE PRESIDENT	\$0	\$0	\$0
Mohammad Chowdhury	TREASURER	\$0	\$0	\$0

Name	Title	Compensation	Other	Related
Belinda Cobb	EMPLOYEE	\$23,680	\$0	\$0
Renita Page	EMPLOYEE	\$19,759	\$0	\$0
David Smythe	DIRECTOR	\$0	\$0	\$0
Janet Froetscher	SECRETARY	\$0	\$0	\$0
Paul Hendrie	DIRECTOR	\$0	\$0	\$0
Linda Adams	DIRECTOR	\$0	\$0	\$0
Jean Campbell	DIRECTOR	\$0	\$0	\$0
Juvi Estrada Veras	DIRECTOR	\$0	\$0	\$0
Diane Schriner	VICE PRESIDENT	\$0	\$0	\$0
Kathy Brewer	PRESIDENT	\$0	\$0	\$0
Mohammad Chowbury	TREASURER	\$0	\$0	\$0

Name	Title	Compensation	Other	Related
Renita Page	EMPLOYEE	\$18,272	\$0	\$0
Belinda Cobb	EMPLOYEE	\$2,080	\$0	\$0
David Smythe	DIRECTOR	\$0	\$0	\$0
Janet Froetscher	DIRECTOR	\$0	\$0	\$0
Mohammad Chowbury	DIRECTOR	\$0	\$0	\$0
Paul Hendrie	DIRECTOR	\$0	\$0	\$0
Glenn Padnick	DIRECTOR	\$0	\$0	\$0
Linda Adams	DIRECTOR	\$0	\$0	\$0
Jean Campbell	DIRECTOR	\$0	\$0	\$0
Juvi Estrada Veras	DIRECTOR	\$0	\$0	\$0
Diane Schriner	TREASURER	\$0	\$0	\$0
Kathy Brewer	PRESIDENT	\$0	\$0	\$0

Name	Title	Compensation	Other	Related
David Smythe	DIRECTOR	\$0	\$0	\$0
Jean Campbell	DIRECTOR	\$0	\$0	\$0
Mohammad Chowbury	DIRECTOR	\$0	\$0	\$0
Paul Hendrie	DIRECTOR	\$0	\$0	\$0
Janet Froetscher	DIRECTOR	\$0	\$0	\$0
Glenn Padnick	DIRECTOR	\$0	\$0	\$0
Linda Adams	DIRECTOR	\$0	\$0	\$0
Juvi Estrada Veras	DIRECTOR	\$0	\$0	\$0
Diane Schriner	TREASURER	\$0	\$0	\$0
Kathy Brewer	PRESIDENT	\$0	\$0	\$0
Renita Page	EMPLOYEE	\$0	\$0	\$0

Name	Title	Compensation	Other	Related
Chesnee Green	EMPLOYEE	\$24,125	\$0	\$0
Linda Adams	DIRECTOR	\$0	\$0	\$0
Glenn Padnick	DIRECTOR	\$0	\$0	\$0
Juvi Estrada Veras	DIRECTOR	\$0	\$0	\$0
Jean Campbell	DIRECTOR	\$0	\$0	\$0
Kathy Brewer	PRESIDENT	\$0	\$0	\$0
Diane Schriner	TREASURER	\$0	\$0	\$0

HIGHEST PAID EMPLOYEES

FISCAL YEAR 2022

Name	Title	Compensation	Other	Related
Jessica Corkran	EMPLOYEE	\$49,199	\$0	\$0

HIGHEST PAID EMPLOYEES

FISCAL YEAR 2021

Name	Title	Compensation	Other	Related
Jessica Corkran	EXECUTIVE DIRECTOR	\$30,393	\$0	\$0

HIGHEST PAID EMPLOYEES

Name	Title	Compensation	Other	Related
Jessica Corkran	EXECUTIVE DIRECTOR	\$0	\$0	\$0

HIGHEST PAID EMPLOYEES

Name	Title	Compensation	Other	Related
Jessica Corkran	EXECUTIVE DIRECTOR	\$33,843	\$0	\$0

Paid Preparers

FISCAL YEAR 2023

Firm Name	Firm EIN	Firm Address	Firm Phone
C RANDALL BROWN CPA	72-1492932	P O BOX 653, DERIDDER LA 70634 USA	337-463-2225

Paid Preparers

FISCAL YEAR 2022

Firm Name	Firm EIN	Firm Address	Firm Phone
C RANDALL BROWN CPA	72-1492932	P O BOX 653, DERIDDER LA 70634 USA	337-463-2225

Paid Preparers

Firm Name	Firm EIN	Firm Address	Firm Phone
C RANDALL BROWN CPA	72-1492932	P O BOX 653, DERIDDER LA 70634 USA	337-463-2225

Organizational Demographics

Who works and leads organizations that serve our diverse communities? This organization has voluntarily shared information to answer this important question and to support sector-wide learning. GuideStar partnered on this section with CHANGE Philanthropy.

Leadership

The organization's leader identifies as:

Race & Ethnicity Decline to state

Gender Identity Female

Sexual Orientation Decline to state

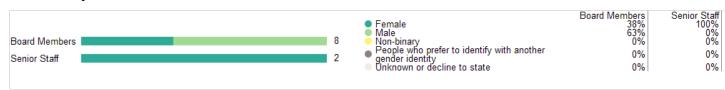
Decline to state

Race & Ethnicity

Disability Status

No data

Gender Identity



Transgender Identity

Sexual Orientation

No data

Disability

No data.

Appendix

Key Documents	
IRS Forms 990	[2] <u>2023 990</u>
	② 2022 990
	Z 2020 990
IRS Forms 990T	Not Available
Audited Financial Statements	Not Available
Key Organization Documents	
	☐ 'Key Revenue & Expense Data from Form 990'
	7 'Key Balance Sheet Data from Form 990'

GuideStar Charity Check

ECD GLOBAL ALLIANCE INC

Aka Erdheim-Chester Disease Global Alliance

715 Davella Dr

Deridder, LA 70634-4731

✓ Foundation Status Code: PC*

✓ Public charity described in section 509(a)(1) or (2)

IRS Publication 78 Details

IRS Pub 78 verified

Organization name Location Most recent IRS Publication 78

Ecd Global Alliance Inc. Deridder, LA September 2025

EIN Deductibility status description Verified with most recent Internal Revenue Bulletin

27-0759192 A public charity (50% deductibility limitation). November 17, 2025

IRS Business Master File Details

IRS BMF

509(a)(1)

Organization name Most recent IRS BMF Reason for Non-Private Foundation Status

ECD GLOBAL ALLIANCE INC September 09 2025 Section 509(a)(1) organization as referred to in Section

170(b)(1)(A)(vi)

EIN IRS subsection Ruling date
27-0759192 This organization is a 501(c)(3) Public Charity 03/2010

Foundation Code Description

15 Organization which receives a substantial part of its support from a governmental unit or the general public

This organization was not included in the Office of Foreign Assets Control Specially Designated Nationals (SDN) list.

On September 8, 2011, the IRS issued regulations which eliminated the advance ruling process for a section 501(c)(3) organization. Learn more

* The Foundation Status Code is the code that foundations are required to provide for each grantee annually on part XV of Form 990PF. Note that this code cannot be derived in some cases (e.g., supporting organizations for which 'type' can't be determined).

<u>IRS Revenue Procedure 2011-33</u> allows grantors to rely on third-party resources, such as GuideStar Charity Check, to obtain required Business Master File (BMF) data concerning a potential grantee's public charity classification under section 509 (a) (1), (2) or (3).

GuideStar Charity Check Data Sources

-GuideStar acquires all IRS data directly from the Internal Revenue Service.

-<u>IRS Publication 78 (Cumulative List of Organizations)</u> lists organizations that have been recognized by the Internal Revenue Service as eligible to receive tax-deductible contributions.

- -The <u>IRS Internal Revenue Bulletin</u> (IRB) lists changes in charitable status since the last Publication 78 release. Between the release of IRS Publication 78 and the subsequent IRS Internal Revenue Bulletin, the IRB date will reflect the most recent release date of IRS Publication 78.
- -The <u>IRS Business Master File</u> lists approximately 1.7 million nonprofits registered with the IRS as tax-exempt organizations.
- -The I<u>RS Automatic Revocation of Exemption List</u> contains organizations that have had their federal tax-exempt status automatically revoked for failing to file an annual return or notice with the IRS for three consecutive years
- -The Foundation Status Code is a value derived by mapping the codes found on the <u>990PF filing instructions</u> to the corresponding codes in the IRS BMF. Note that not all codes are able to be mapped due to insufficient data.
- -The Office of Foreign Assets Control (OFAC) <u>Specially Designated Nationals (SDN) list</u> organizations that are owned or controlled by targeted individuals, groups, and entitles, such as terrorists or narcotics traffickers. Their assets are blocked and U.S. persons are generally prohibited from dealing with them.