Stichting Friedreich's Ataxia Research Alliance Europe, Amsterdam

ANNUAL REPORT

Stichting Friedreich's Ataxia Research Alliance Europe
vested in Amsterdam
Annual report 2025

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CONFIDENTIAL
Stichting Friedreich's Ataxia Research Alliance Europe
To the attention of the board
Jachthavenweg 111
1081 KM AMSTERDAM

Etten-Leur, 27-07-2026

Dear board,

1.1 ACCOUNTANT'S COMPILATION REPORT

The financial statements of Stichting Friedreich's Ataxia Research Alliance Europe, Amsterdam, have been compiled by us using the information provided by you. The financial statements comprise the balance sheet as at 31 December 2025 and the statement of activities for the year 2025 for the year then ended with the accompanying explanatory notes. These notes include a summary of the accounting policies which have been applied.

This compilation engagement has been performed by us in accordance with Dutch law, including the Dutch Standard 4410, 'Compilation engagements', which is applicable to accountants. The standard requires us to assist you in the preparation and presentation of the financial statements. To this end we have applied our professional expertise in accounting and financial reporting.

In a compilation engagement, you are responsible for ensuring that you provide us with all relevant information and that this information is correct. Therefore, we have conducted our work, in accordance with the applicable regulations, on the assumption that you have fulfilled your responsibility. To conclude our work, we have read the financial statements as a whole to consider whether the financial statements as presented correspond with our understanding of Stichting Friedreich's Ataxia Research Alliance Europe. We have not performed any audit or review procedures which would enable us to express an opinion or a conclusion as to the fair presentation of the financial statements.

During this engagement we have complied with the relevant ethical requirements prescribed by the 'Verordening Gedrags- en Beroepsregels Accountants' (VGBA). You and other users of these financial statements may therefore assume that we have conducted the engagement in a professional, competent and objective manner and with due care and integrity and that we will treat all information provided to us as confidential.

1.2 GENERAL

INCORPORATION FOUNDATION

The foundation was incorporated on May 15, 2023.

ACTIVITIES

The activities of Stichting Friedreich's Ataxia Research Alliance Europe (FARA Europe), having its legal seat at Amsterdam, primarily consist of:

- to pursue educational, scientific and research activities, programs and initiatives which will work toward the development of treatments and cures for Friedreich's Ataxia (FA);
- to promote clinical, scientific, and biomedical research through research grants, seminars and conferences;
- to serve as a patient advocacy group, in particular to educate the public on FA to improve diagnosis, management and development of treatments;
- to cooperate with and support other organizations that are organised and operated for similar purposes;
- to focus national and international attention on FA;
- to rally together patients, families, caregivers, genetic support groups, health care providers, the medical community, researchers and scientists, affiliated organizations and businesses as advocates for action, advances and change to raise awareness, promote research and improve clinical outcomes;
- to educate the public about FA and facilitate public access to information resources and support organizations; and
- to accept, hold, invest, reinvest and administer any gifts, legacies, bequests, devices, funds and property of any sort or nature, and to use, expend, or donate the income or principle thereof for, and to devote the same to, the foregoing objects of the foundation,

as well as to carry out all which is incidental or conducive to the above, all in the broadest sense.

ANBI

From May 15, 2023, the foundation is registered as an ANBI (Algemeen Nut Beogende Instelling).

BOARD OF DIRECTORS

The board of directors consists of R.C. Acton (Treasurer), P.E. Avery (Chairman), B.T. Brennan (Secretary), G. Manfredi, H.M.S. Puccio, P.M. Ritschel, T.E. Hamilton, T.A. Brenninkmeijer and M. Pandolfo.

1.3 SUMMARY FINANCIAL INFORMATION

	31-12-2025	31-12-2024	31-12-2023
	€	€	€
ASSETS			
Current assets			
Receivables	90,021	68,466	294,412
Cash and cash equivalents	109,233	302,876	-
Total assets	199,254	371,342	294,412
EQUITY AND LIABILITIES			
Net assets	4,235	220,743	277,098
Current liabilities, accruals and deferred income	195,019	150,599	17,314
Total equity and liabilities	199,254	371,342	294,412

	2025	2024	2023
	€	€	€
Benefits	198,131	148,850	294,412
Gross margin	198,131	148,850	-
Total of operating result	-202,368	-58,913	-17,313
Total of net result	-216,508	-56,355	277,099
Net assets	4,235	220,743	277,098

We shall be pleased to provide you further information you may require.

Yours sincerely,

ESJ Accountants & Belastingadviseurs

ValidSigned door André Groeneveld
op 27-07-2026

A. Groeneveld
Accountant-Administratieconsulent

2. MANAGEMENT BOARD'S REPORT

The activities

FARA Europe's primary focus is supporting FA research, specifically the European research activities of the FA Global Clinical Consortium (FA GCC). Launched in 2023, the FA GCC's mission is to accelerate the development of treatments for FA by empowering patients and researchers, advancing understanding of natural history, conducting research, and building infrastructure that facilitates clinical research globally. The Consortium comprises a Funding Board (FARA and FARA Europe), a Scientific Steering Committee, an Operations and Management Team, Working Groups, a Patient Advocacy/Advisory Team, and investigator members at each clinical site. Participation spans 33 sites across 18 countries.

Each FA GCC clinical site receives funding to participate in the UNIFIED Natural History Study (UNIFAI; https://clinicaltrials.gov/study/NCT06016946) and to:
- Identify and validate clinical outcome measures and biomarkers necessary for clinical trials in FA;
- Facilitate the implementation and delivery of clinical trials;
- Share data and resources to advance treatments for FA;
- Define best clinical practices and support the highest standard of clinical care for patients.

As of year-end 2025, 14 European research sites across 8 countries had been activated, and more than 2,900 individuals had been enrolled in the UNIFAI study. In addition to UNIFAI, a second study was initiated through the FA GCC, sponsored by Biogen: An Observational, Multinational, Post-Marketing Registry of Omaveloxolone-Treated Patients With Friedreich's Ataxia (PAS study; https://clinicaltrials.gov/study/NCT06623890). As many European sites commenced research activities for both the UNIFAI and PAS studies during 2025, funding needs are expected to increase in 2026 and 2027 as additional study visits are conducted and further sites are activated. The Board believes that continued investment in global clinical research infrastructure and the continuation of natural history studies are essential to fulfilling our mission.

FARA Europe's revenue is derived primarily from Friedreich ataxia foundations—including FARA—and individual donors. A portion of the funds received from FARA represents funding provided by Biogen to support PAS study activities.

3. FINANCIAL STATEMENTS

3.1 BALANCE SHEET AS AT 31 DECEMBER 2025

	31 December 2025		31 December 2024	
	€	€	€	€
ASSETS				
CURRENT ASSETS				
Receivables				
Other receivables, prepayments and accrued income		90,021		68,466
Cash and cash equivalents		109,233		302,876
		199,254		371,342

	31 December 2025		31 December 2024	
	€	€	€	€
EQUITY AND LIABILITIES				
NET ASSETS				
General reserve		4,235		220,743
CURRENT LIABILITIES, ACCRUALS AND DEFERRED INCOME				
Trade payables	110,287		11,045	
Other liabilities and accrued expenses	84,732		139,554	
		195,019		150,599
		199,254		371,342

3.2 STATEMENT OF ACTIVITIES FOR THE YEAR 2025

	2025		2024	
	€	€	€	€
Benefits				
Other income		198,131		148,850
		198,131		148,850
Expenses				
Other operating expenses		400,499		207,763
Total of operating result		-202,368		-58,913
Currency translation differences		-14,140		2,558
Total of net result		-216,508		-56,355
Appropriation of result				
General reserve		-216,508		-56,355

3.3 NOTES TO THE FINANCIAL STATEMENTS

Entity information

Registered office, legal form and registration number at the Chamber of Commerce

The registered and actual address of Stichting Friedreich's Ataxia Research Alliance Europe is Jachthavenweg 111, 1081 KM in Amsterdam, Nederland. Stichting Friedreich's Ataxia Research Alliance Europe is registered at the Chamber of Commerce under number 90213602.

General notes

The most important activities of the entity

The activities of FARA Europe consist mainly of:
- to promote clinical, scientific and biomedical research through research grants, seminars and conferences. Through the year ended 2025, the primary research funded by FARA Europe was the UNIFAI Study, a global, multicenter, prospective, observational natural history study that can be used to understand the disease progression and support the development of safe and effective drugs and biological products for FA.
- to pursue educational, scientific and research activities, programs and initiatives which will work toward the development of treatments and cures for FA;
- to serve as a patient advocacy group, in particular to educate the public of the importance of funding of biomedical research towards FA;
- to cooperate with and support other organizations that are organised and operated for similar purposes;
- to focus national and international attention on FA;
- to rally together patients, families, caregivers, genetic support groups, health care providers, the medical community, researchers and scientists, affiliated organizations and businesses as advocates for action, advances and change to raise awareness, promote research and improve clinical outcomes;
- to educate the public about FA and facilitate public access to information resources and support organizations; and
- to accept, hold, invest, reinvest and administer any gifts, legacies, bequests, devices, funds and property of any sort or nature, and to use, expend, or donate the income or principle thereof for, and to devote the same to, the foregoing objects of the foundation,

as well as to carry out all which is incidental or conducive to the above, all in the broadest sense.

Disclosure of group structure

FARA Europe works collaboratively with the Friedreich's Ataxia Research Alliance (FARA), a non-profit incorporated under the laws of the District of Columbia. The financial statements of FARA Europe are included in the consolidated financial statements of FARA (https://www.curefa.org/financials/).

Disclosures about estimates, judgements, assumptions and uncertainties

In applying the principles and policies for drawing up the financial statements, the directors of FARA Europe make different estimates and judgments that may be essential to the amounts disclosed in the financial statements. If it is necessary in order to provide the transparency required under Book 2, article 362, paragraph 1, the nature of these estimates and judgments, including related assumptions, is disclosed in the notes to the relevant financial statement item.

General accounting principles

The accounting standards used to prepare the financial statements

The financial statements have been prepared in accordance with the Dutch Accounting Standards for micro and small legal entities, including Chapter C1 “Small not-for-profit organisations”, as published by the Dutch Accounting Standards Board (‘Raad voor de Jaarverslaggeving’). These standards incorporate relevant provisions of Title 9 of Book 2 of the Dutch Civil Code, insofar as necessary to provide the required insight into the foundation’s equity and result.

Assets and liabilities are generally valued at historical cost, production cost or at fair value at the time of acquisition. If no specific valuation principle has been stated, valuation is at historical cost.

Conversion of amounts denominated in foreign currency

The financial statements are presented in euros, which is the functional and presentation currency of Stichting Friedreich's Ataxia Research Alliance Europe.

Basis of conversion and processing of exchange rate differences relating to foreign currency transactions for the balance sheet

Monetary assets and liabilities in foreign currencies are converted to the closing rate of the functional currency on the balance sheet date. The translation differences resulting from settlement and conversion are credited or charged to the statement of activities.

Non-monetary assets valued at historical cost in a foreign currency are converted at the exchange rate on the transaction date.

Non-monetary assets valued at fair value in a foreign currency are converted at the exchange rate on the date on which the fair value was determined.

Accounting principles

Receivables

Receivables are initially valued at the fair value of the consideration to be received. Receivables are subsequently valued at the amortised cost price. If there is no premium or discount and there are no transaction costs, the amortised cost price equals the nominal value of the accounts receivable. If payment of the receivable is postponed under an extended payment deadline, fair value is measured on the basis of the discounted value of the expected revenues. Interest gains are recognised using the effective interest method. Provisions for bad debts are deducted from the carrying amount of the receivable.

Cash and cash equivalents

Cash at banks and in hand represent cash in hand, bank balances and deposits with terms of less than twelve months. Overdrafts at banks are recognised as part of debts to lending institutions under current liabilities. Cash at banks and in hand is valued at nominal value.

Current assets

Current assets are initially valued at the fair value of the consideration to be received. Trade receivables are subsequently valued at the amortised cost price. If payment of the receivable is postponed under an extended payment deadline, fair value is measured on the basis of the discounted value of the expected revenues. Interest gains are recognised using the effective interest method. Provisions for bad debts are deducted from the carrying amount of the receivable.

Current liabilities

On initial recognition current liabilities are recognised at fair value. After initial recognition current liabilities are recognised at the amortised cost price, being the amount received taking into account premiums or discounts and minus transaction costs. This is usually the nominal value.

Accounting principles for determining the result

The result is the difference between the realisable value of the services provided and the costs and other charges during the year. The results on transactions are recognised in the year in which they are realised.

Income

Funding for the Organization's activities is achieved almost entirely through foundation, corporate and other support, contributions, and in-kind contributions, including unconditional promises to give. These donations provide funding to be used to support the Organization's mission. As the donors are not receiving a benefit as a result of these transactions, the donations are considered to be contributions to the Organization.

3.4 NOTES TO THE BALANCE SHEET AS AT 31 DECEMBER 2025

ASSETS

Current assets

Receivables

	31-12-2025	31-12-2024
	€	€
Other receivables, prepayments and accrued income		
Grants receivable	90,021	68,466

Cash and cash equivalents

ING Bank N.V.	79,105	-
Citizens bank	30,128	302,876
	109,233	302,876

EQUITY AND LIABILITIES

Net assets

Movements in equity were as follows:

	General reserve
	€
Balance as at 1 January 2025	220,743
Appropriation of result	-216,508
Balance as at 31 December 2025	4,235

	2025	2024
	€	€
General reserve		
Balance as at 1 January	220,743	277,098
Appropriation of result	-216,508	-56,355
Balance as at 31 December	4,235	220,743

Current liabilities, accruals and deferred income

	31-12-2025	31-12-2024
	€	€
Trade payables		
Accounts payable	110,287	11,045
Other liabilities and accrued expenses		
Research grants	79,732	134,080
Accounting and administration	5,000	5,474
	84,732	139,554

Contingent assets and liabilities

Disclosure of off-balance sheet commitments

FARA Europe has ongoing research agreements that are renewed annually. The commitments arising from these agreements amount to € 80,000 for 2026.

3.5 NOTES TO THE STATEMENT OF ACTIVITIES FOR THE YEAR 2025

	2025	2024
	€	€
Benefits		
Other income	198,131	148,850
Other income		
Support/grant	120,163	115,146
Nonprofit and Foundation Contributions	76,052	30,000
Advising and consulting	1,916	3,272
Other	-	432
	198,131	148,850

Other operating expenses

	2025	2024
Office expenses	58	58
General expenses	400,441	207,705
	400,499	207,763
Office expenses		
Telephone and fax expenses	58	58
General expenses		
Research grants and expenses	376,166	160,389
Accounting and advicing	22,012	8,192
Webhosting and subscriptions	496	772
Travelling and hotel expenses	1,665	1,145
Outside contract services including Data Protection Officer	-	36,900
Bank expenses	101	306
Other general expenses	1	1
	400,441	207,705

ANALYSIS OF DIFFERENCE REALIZATION WITH BUDGET

	2025	2025	Difference	
	€	€	€	%
Benefits	198,131	96,609	101,522	105.1
	198,131	96,609	101,522	105.1
Other operating expenses	400,499	597,550	-197,051	-33.0
Total of sum of expenses	400,499	597,550	-197,051	-33.0
Total of operating result	-202,368	-500,941	298,573	59.6
Financial income and expense	-14,140	-	-14,140	-
Total of net result	-216,508	-500,941	284,433	56.8

Disclosure of analysis of differences between the budget and actuals

In 2025, FARA Europe's total revenue exceeded budget by approximately Euro 100.000 representing both foundation grants and individual gifts that exceeded the budgeted amount. For the same period, FARA Europe's spending on grant and administrative activities was less than budgeted, although still representative of increases over 2024 as more clinical sites in Europe opened to the FA GCC activities and more study visits occurred as patient enrollments increased. Overall results were favorable to budget with expectations that 2026 activities will bring additional resources to sustain and grow the foundation's activities.

3.6 OTHER NOTES

Average number of employees

Disclosure of average number of employees during the period

The foundation has no employees in 2025. The foundation gets administrative support from Friedreich's Ataxia Research Alliance as described in note 3.4 Disclosure of group structure.

Amsterdam,
Stichting Friedreich's Ataxia Research Alliance Europe

R.C. Acton Treasurer Director ValidSigned door R.C. Acton op 27-07-2026	P.E. Avery Chairman Director ValidSigned door P.E. Avery op 28-07-2026	B.T. Brennan Secretary Director ValidSigned door B.T. Brennan op 03-08-2026
G. Manfredi Director ValidSigned door G. Manfredi op 28-07-2026	H.M.S. Puccio Director ValidSigned door H.M.S. Puccio op 27-07-2026	P.M. Ritschel Director ValidSigned door P.M. Ritschel op 27-07-2026
T.E. Hamilton Director ValidSigned door T.E. Hamilton op 28-07-2026	T.A. Brenninkmeijer Director ValidSigned door T.A. Brenninkmeijer op 27-07-2026	M. Pandolfo Director ValidSigned door M. Pandolfo op 28-07-2026