

**STICHTING WORLD DUCHENNE ORGANIZATION
AT VEENENDAAL**
Annual Report 2024

January 28, 2026

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AUDITOR'S REPORT

To the board of
Stichting World Duchenne Organization
Landjuweel 16-8
3905 PG Veenendaal

<i>Reference</i>	<i>Processed by</i>	<i>Date</i>
11200	HdB/IL	January 28, 2026

Dear members of the Executive Board,

We hereby send you the report regarding the financial statements for the year 2024 of the foundation.

1 ENGAGEMENT

In accordance with your instructions we have compiled the annual account 2024 of the foundation, including the balance sheet with counts of € 179,279 and the profit and loss account with a result of € 35,716.

2 ACCOUNTANT'S COMPILATION REPORT

To: the management

The financial statements of Stichting World Duchenne Organization at Veenendaal have been compiled by us using the information provided by you. The financial statements comprise the balance sheet as at December 31, 2024 and the profit and loss account for the year 2024 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 in accordance with Part 9 of Book 2 of the Civil Code. 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 World Duchenne Organization. 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.

For further information on the nature and scope of a compilation engagement and the VGBA we refer you to www.nba.nl/uitleg-samenstellingsverklaring.

3 RESULTS

3.1 Comparative overview

The result for 2024 amounts to € 36,000 compared to € 4,000 for 2023. The results for both years can be summarized as follows:

	Saldo 2024	Saldo 2023
	€	€
Income		
Income from individuals & Legal entities	285,070	90,483
Subsidies	122,906	142,890
Gross margin	<u>407,976</u>	<u>233,373</u>
Expenses		
Expenditure on activities	253,570	122,279
Expenditure on other activities	34,234	42,291
	<u>287,804</u>	<u>164,570</u>
Management and administration		
Employee expenses	28,506	42,847
Other operating expenses	57,273	22,332
Som der lasten	<u>85,779</u>	<u>65,179</u>
Result	<u>34,393</u>	<u>3,624</u>
Financial income and expenses	1,323	511
Balance	<u><u>35,716</u></u>	<u><u>4,135</u></u>

4 FINANCIAL POSITION

The balance sheet can be summarized as follows:

	12/31/2024		12/31/2023	
	€	€	€	€
Long term funds:				
Reserves and funds		152,604		116,889
This amount is applied as follows:				
Receivables, prepayments and accrued income	44,539		7,630	
Cash and cash equivalents	134,740		126,556	
		179,279		134,186
Debit: Short-term debt		26,675		17,297
Working capital		152,604		116,889

Yours sincerely,

Stolwijk registeraccountants en belastingadviseurs B.V.
I.M. van Lexmond AA
Accountant-Administratieconsulent

Digitaal ondertekend door:

Inge van Lexmond
28 januari 2026 12:15 +01:00

MANAGEMENT BOARD REPORT

GENERAL

On May 21, 2007 the Stichting World Duchenne organization (then called Stichting United Parent Project muscular Dystrophy) was officially founded. Stichting World Duchenne Organization (Coe file 30226334) has its registered office in Zeist, The Netherlands.

BOARD MEMBERS

Elizabeth Vroom, chair
Ed Snitselaar, treasurer
Patricia Furlong
Sally Hofmeister
Dimitrios Athanasiou
Ialina Vinci
Karolina Podolska
Graciela Méndez
Aida Adra

MISSION AND VISION

The World Duchenne Organization, founded by parents of children with Duchenne Muscular Dystrophy, is a worldwide organization dedicated to finding a cure and viable treatments for Duchenne and Becker Muscular Dystrophy, to promoting good standards of care, and to inform parents around the globe. Duchenne Muscular Dystrophy is a genetic, progressive and ultimately fatal disease. Becker Muscular Dystrophy is a milder form. There is a compelling need to ensure that wherever they are in the world, patients suffering from this disease can benefit from a standard of care that is informed by the best practice of the best clinicians from all over the world.

It is equally important that the information available to parents is contemporary, truthful and is based upon the latest research. It is important that the needs of the Duchenne families are the starting point for initiatives concerning them. There is a lot to win if their experience and expertise is utilized. People with disabilities and diseases know what it means to have this condition. It means they will bring in a different perspective to caregivers, researchers or policymakers. Their questions and needs are based on their own experiences, interests, and vision.

MEMBERS

In 2024, the organization had 52 member organizations from 39 countries.
For all members see <https://www.worldduchenne.org/wdo-members/>

ACTIVITIES DURING THE YEAR 2024

Besides supporting our members and sending regular updates to our community, the foundation organised advocacy and educational activities and participated in expert meetings about Care and Drug development.

We welcomed new [WDO Member](#) and [WDO Aspiring Member](#) organizations. Through the [Duchenne Community Advisory Board](#), we provided the environment for discussions between pharmaceutical companies with patient experts. Subsequently, WDO remains to be actively involved as a partner in European funded projects such as [BEAMER](#), [BIND](#) (which ended in 2024 and post project activities were initiated for the establishment of BIND Association, [EURO-NMD Registry Hub](#) (post-project support and contribution) and [Trials@Home](#)).

Through the [Accredited Duchenne Care Centers program](#) we are not only accrediting hospitals treating patients according to the International Standards of Care but also help these hospitals to improve the quality and organisation of the provided care. The ADC program is supported by an international Advisory Board of Duchenne Care Experts

The annual [Duchenne Care Conference](#) is a multi-day online conference where important topics regarding Duchenne and Becker Care are presented by the world experts. Participation is for free so also Health Care Professionals in remote and/or low income countries can participate. Yearly hundreds of Health Care Professionals from all continents sign up. Simultaneous translation available.

Our board members presented at a series of international conferences on topics such as policy, regulations, drug development, research, data and care.

World Duchenne Organization is member of:

[EMA \(eligible member\)](#)

[EURORDIS](#)

[European Patient Forum](#)

[ENMC](#)

[Rare Disease International](#)

In 2024 board members of WDO attended meetings of these organisations

In the year of 2024, the World Duchenne Organization organized the following events and activities:

KEY ACTIVITIES: WORLD DUCHENNE ORGANIZATION – 2024
February
Meeting: WDO Member Meeting 2024 Rome
March
Activate the DMD Emergency Program for families affected by the floods in Brasil Accreditation of Instituto Nacional de rehabilitation Luis Guillermo Ibarra Mexico
May
Publication of WDO's White paper on New born screening Organisation of Global Duchenne Care Conference with over 700 participants from 72 countries
June
Accreditation of The Robert Jones and Agnes Hunt Orthopaedic Hospital in Oswestry
September
World Duchenne Awareness Day: Documentary ' Road to Independence ' Hosting the BINDproject.eu webinar on the role of dystophin in the brain.

Launch of [ERDERA](#) partnership

October

November

Start of the [Global DMD Adult Group](#), initiated by adults with Duchenne Muscular Dystrophy (DMD)

Participate in [HMA EMA multistakeholder workshop](#) on Artificial Intelligence

December

Conference: Co-organize [Duchenne Patient Academy 2024](#) a global training for Patient Advocates.

Accreditation [Antalya Neuromuscular Center Turkey](#)

FINANCIAL STATEMENTS

Stichting World Duchenne Organization, Veenendaal

1 BALANCE SHEET AS AT DECEMBER 31, 2024
(after result appropriation)

		December 31, 2024		December 31, 2023	
		€	€	€	€
ASSETS					
CURRENT ASSETS					
Receivables, prepayments and accrued income	(1)	44,539		7,630	
Cash and cash equivalents	(2)	134,740		126,556	
			179,279		134,186
				179,279	134,186

	December 31, 2024		December 31, 2023	
	€	€	€	€
EQUITY AND LIABILITIES				
RESERVES AND FUNDS (3)				
Allocation reserves	309,836		298,604	
Unrestricted funds, general	<u>-157,232</u>		<u>-181,715</u>	
		152,604		116,889
CURRENT LIABILITIES (4)				
Accounts payable	1,246		2,099	
Taxes and social securities	11,253		917	
Other liabilities and Accruals and deferred income	<u>14,176</u>		<u>14,281</u>	
		26,675		17,297
		<u>179,279</u>		<u>134,186</u>

2 STATEMENT OF THE FINANCIAL ACCOUNTS OVER 2024

	Balance 2024	Balance 2023
	€	€
Income		
Income from individuals & Legal entities	(5) 285,070	90,483
Subsidies	(6) 122,906	142,890
Sum of income	407,976	233,373
Expenses		
Expenditure on activities	(7) 253,570	122,279
Expenditure on other activities	(8) 34,234	42,291
	287,804	164,570
Management and administration		
Employee expenses	(9) 28,506	42,847
Other operating expenses	(10) 57,273	22,332
	85,779	65,179
Balance before financial income and expense		
Interest and similar income	(11) 34,393	3,624
	1,323	511
Result	35,716	4,135
Appropriation of the results		
Allocation reserves	11,232	-93,367
Unrestricted funds, general	24,484	97,502
	35,716	4,135

3 NOTES TO THE FINANCIAL STATEMENTS

GENERAL

Registered office, legal form and registration number at the chamber of commerce

The registered and actual address of Stichting World Duchenne Organization (CoC file 30226334) is Landjuweel 16-8, 3905 PG, Veenendaal.

Estimates

In applying the principles and policies for drawing up the financial statements, the directors of Stichting World Duchenne Organization 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 FOR THE PREPARATION OF THE ANNUAL ACCOUNTS

The annual accounts have been prepared in accordance with the guidelines for annual reporting for small organisations without profit strife (Rjk C1). These are in line with the requirements for small legal entities that fall under Title 9 Book 2 of the Dutch Civil Code.

Valuation of assets and liabilities and determination of the result takes place under the historical cost convention. Unless presented otherwise at the relevant principle for the specific balance sheet item, assets and liabilities are presented at nominal value.

Income and expenses are allocated to the year to which they relate. Profits are only included insofar as they have been realized on the balance sheet date. Liabilities and possible losses that originate before the end of the reporting year are taken into account if they have become known before the preparation of the annual accounts.

ACCOUNTING PRINCIPLES APPLIED TO THE VALUATION OF ASSETS AND LIABILITIES

Receivables and deferred assets

Upon initial recognition the receivables on and loans to participations and other receivables are valued at fair value and then valued at amortised cost, which equals the face value, after deduction of any provisions. The fair value and amortised cost equal the face value. Any provisions for the risk of doubtful debts are deducted. These provisions are determined based on individual assessment of the receivables.

Cash and cash equivalents

The cash is valued at face value. If cash equivalents are not freely disposable, then this has been taken into account in the valuation.

Allocation reserves

The allocation reserves are reserves with a more limited allocation, whereby the restriction has been imposed by the provider of the grant.

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 THE DETERMINATION OF THE RESULT

General

The result is defined as the difference between the income one hand and, on the other hand, the costs and expenses for that year, valued at historical costs.

Determination of the result

The result is determined based upon the difference between the nett income and the costs and other expenses taking into account the aforementioned valuation principles.

Expenditure on activities

The expenditure on activities consists of the cost directly related to the activities.

Employee expenses

The benefits payable to personnel are recorded in the profit and loss account on the basis of the employment conditions.

Financial income and expenses

Interest income and interest expenses

Interest income and expenses are recognised on a pro rata basis, taking account of the effective interest rate of the assets and liabilities to which they relate. In accounting for interest expenses, the recognised transaction expenses for loans received are taken into consideration.

4 NOTES TO THE BALANCE SHEET AS OF DECEMBER 31, 2024

ASSETS

1. Receivables, prepayments and accrued income

	<u>12/31/2024</u>	<u>12/31/2023</u>
	€	€
<i>Accounts receivable</i>		
Accounts receivables	60,539	6,817
Doubtful debtor provision	-16,000	-
	<u>44,539</u>	<u>6,817</u>
 <i>Other receivables and accruals</i>		
Other receivables	<u>-</u>	<u>813</u>
 2. Cash and cash equivalents		
ABN Amro NL10ABNA0120254093	345	431
PayPal WCN3VRLEQWUZL	14,793	13,939
ABN Amro NL91ABNA0417429207	29,491	23,399
ABN Amro NL92ABNA0423265970	90,111	88,787
	<u>134,740</u>	<u>126,556</u>

The liquid resources are valued at nominal value. The liquid resources available as at December 31, 2024 are freely available to the Stichting World Duchenne Organization.

EQUITY AND LIABILITIES

3. Reserves and funds

	12/31/2024	12/31/2023
	€	€
Allocation reserves		
Allocation reserve Trials at Home project	167,326	171,131
Allocation reserve BIND	69,713	93,456
Allocation reserve BEAMER	41,523	34,017
Allocation reserve ERDERA	31,274	-
	<u>309,836</u>	<u>298,604</u>

	2024	2023
	€	€

Allocation reserve Trials at Home project

Carrying amount as of January 1	171,131	78,396
Result allocation	-3,805	92,735
Carrying amount as of December 31	<u>167,326</u>	<u>171,131</u>

This is the part of the subsidy received from the European Commission that has not yet been spent on the project Trails at Home.

Allocation reserve BIND

Carrying amount as of January 1	93,456	80,765
Result allocation	-23,743	12,691
Carrying amount as of December 31	<u>69,713</u>	<u>93,456</u>

This is the part of the subsidy received from the European Commission that has not yet been spent on the project BIND.

Allocation reserve BEAMER

Carrying amount as of January 1	34,017	59,165
Result allocation	7,506	-25,148
Carrying amount as of December 31	<u>41,523</u>	<u>34,017</u>

This is the part of the subsidy received from the European Commission that has not yet been spent on the project BEAMER.

Allocation reserve ERDERA

Carrying amount as of January 1	-	-
Result allocation	31,274	-
Carrying amount as of December 31	<u>31,274</u>	<u>-</u>

This is the part of the subsidy received from the European Commission that has not yet been spent on the project ERDERA.

Stichting World Duchenne Organization, Veenendaal

	2024	2023
	€	€
<i>Unrestricted funds, general</i>		
Carrying amount as of January 1	-181,716	-279,217
Allocation of financial year net result	24,484	97,502
Carrying amount as of December 31	<u>-157,232</u>	<u>-181,715</u>

4. Current liabilities

	12/31/2024	12/31/2023
	€	€
<i>Accounts payable</i>		
Accounts payable	<u>1,246</u>	<u>2,099</u>

Taxes and social securities

VAT	11,253	-
Pay-roll tax	-	917
	<u>11,253</u>	<u>917</u>

VAT

VAT fourth quarter	12,020	-
VAT third quarter	-888	-
VAT supplement 2024	121	-
	<u>11,253</u>	<u>-</u>

Accruals and deferred income

Other costs	-	105
Current account Duchenne Data Foundation	14,176	14,176
	<u>14,176</u>	<u>14,281</u>

5 NOTES TO THE STATEMENT OF FINANCIAL ACTIVITIES 2024

	Balance 2024	Balance 2023
	€	€
5. Income from individuals & Legal entities		
Donations and gifts	1,899	2,244
Membershipfee	18,585	31,739
Duchenne Patient Academy	-	14,000
Donations Ukraine emergency fund	-	22,500
Donations Turkey emergency fund	-	10,000
Donations ADC Data Project	-	5,000
Donations CAB	264,586	5,000
	<u>285,070</u>	<u>90,483</u>
6. Subsidies		
European Commission subsidy Trials at Home	49,610	119,394
European Commission subsidy BIND	-	23,496
European Commission subsidy BEAMER	41,056	-
European Commission subsidy ERDERA	32,240	-
	<u>122,906</u>	<u>142,890</u>
7. Expenditure on activities		
Expenses CAB	65,668	-
Expenses Trials at Home	53,415	26,659
Expenses BIND	23,743	10,804
Expenses WDO	5,345	2,187
Expenses WDAD	20,901	35,366
Expenses BEAMER	83,532	47,263
Expenses ERDERA	966	-
	<u>253,570</u>	<u>122,279</u>
8. Expenditure on other activities		
Expenses Accreditation Duchenne Centers project	34,234	30,976
Expenses Turkey emergency fund	-	10,000
Expenses Empowered Project	-	1,315
	<u>34,234</u>	<u>42,291</u>

Het totaal bestedingen aan doelstellingen uitgedrukt in een percentage van de totale baten is:

2024: 70.5 %

2023: 70.5 %

Het totaal bestedingen aan doelstellingen uitgedrukt in een percentage van de totale lasten is:

2024: 77.0 %

2023: 71.6 %

Stichting World Duchenne Organization, Veenendaal

	Balance 2024	Balance 2023
	€	€
9. Employee expenses		
Wages and salaries	15,957	34,062
Social security charges	5,221	5,787
Other personnel costs	7,328	2,998
	<u>28,506</u>	<u>42,847</u>
<i>Wages and salaries</i>		
Gross wages	28,021	31,647
Gross holidaypay	2,150	2,415
Sick pay received	-14,214	-
	<u>15,957</u>	<u>34,062</u>
<i>Social security charges</i>		
Other social charges	<u>5,221</u>	<u>5,787</u>
<i>Other personnel costs</i>		
Travelling expenses	1,985	1,977
Education allowance and training costs	5,343	1,021
	<u>7,328</u>	<u>2,998</u>
Staff		
In 2024 0.5 employees were employed, converted to full-time (2023: 0.4)		
10. Other operating expenses		
Office expenses	12,398	13,795
Publicity expenses	16,000	97
General expenses	28,875	8,440
	<u>57,273</u>	<u>22,332</u>
<i>Office expenses</i>		
Automation costs	5,316	7,133
Telephone and internet costs	1,324	1,204
Contributions and subscriptions	5,758	5,458
	<u>12,398</u>	<u>13,795</u>
<i>Publicity expenses</i>		
Website costs	-	97
Allocation to accrual doubtful debtors	16,000	-
	<u>16,000</u>	<u>97</u>

Stichting World Duchenne Organization, Veenendaal

	<u>Balance 2024</u>	<u>Balance 2023</u>
	€	€
<i>General expenses</i>		
Audit costs	6,892	8,571
Audit costs previous years	-	-1,398
Liability insurance	962	962
Tax authority fines	100	-
Banking costs	1,009	335
Non-deductible VAT	19,754	-
Other general expenses	158	-30
	<u>28,875</u>	<u>8,440</u>
11. Interest and similar income		
Bank interest	<u>1,323</u>	<u>511</u>

OTHER INFORMATION

OTHER INFORMATION

1 Audit

the foundation has utilized the exemption from an audit by virtue of art. 2:396, paragraph 7 of the Dutch Civil Code.

Gegevens bedrijf

Onderneming Stichting World Duchenne Organization
Btw-nummer NL817990161B01
Tijdvak Jaar

	Bedrag waarover omzetbelasting wordt berekend Omzetbelasting	
	€	€
1: Prestaties binnenland		
1a: Leveringen/diensten belast met hoog tarief	0	0
1b: Leveringen/diensten belast met laag tarief	0	0
1c: Leveringen/diensten belast met overige tarieven, behalve 0%	0	0
1d: Privégebruik	0	0
1e: Leveringen/diensten belast met 0% of niet bij Stichting World Duchenne Organization belast	0	
2: Verleggingsregeling binnenland		
2a: Leveringen/diensten waarbij de omzetbelasting naar Stichting World Duchenne Organization is verlegd	0	0
3: Prestaties naar of in het buitenland		
3a: Leveringen naar landen buiten de EU (uitvoer)	0	
3b: Leveringen naar of diensten in landen binnen de EU	32.000	
3c: Installatie/afstandsverkopen binnen de EU	0	
4: Prestaties vanuit het buitenland aan u geleverd		
4a: Leveringen/diensten uit landen buiten de EU	0	0
4b: Leveringen/diensten uit landen binnen de EU	87.343	18.342
5: Voorbelasting en kleineondernemersregeling		
5a: Verschuldigde omzetbelasting		18.342
5b: Voorbelasting		-3.878
Saldo eerder opgegeven		-14.343
Te betalen omzetbelasting		121

U ontvangt een aanslag nadat de aangifte is ingediend. In deze aanslag staan een betalingskenmerk en een betalingstermijn vermeld.