

**STICHTING WORLD DUCHENNE ORGANIZATION
AT VEENENDAAL**
Annual Report 2023

January 15, 2026

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AUDITOR'S REPORT

To the board of

<i>Reference</i>	<i>Processed by</i>	<i>Date</i>
11200	HdB/IL	January 15, 2026

Dear members of the Executive Board,

We hereby send you the report regarding the financial statements for the year 2023 of the foundation.

1 ENGAGEMENT

In accordance with your instructions we have compiled the annual account 2023 of the foundation, including the balance sheet with counts of € 134,186 and the profit and loss account with a result of € 4,135.

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, 2023 and the profit and loss account for the year 2023 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 2023 amounts to € 4,000 compared to € 26,000 for 2022. The results for both years can be summarized as follows:

	Saldo 2023	Saldo 2022
	€	€
Income		
Income from individuals & Legal entities	90,483	60,552
Subsidies	142,890	163,549
Gross margin	<u>233,373</u>	<u>224,101</u>
Expenses		
Expenditure on activities	122,279	91,977
Expenditure on other activities	42,291	29,757
	<u>164,570</u>	<u>121,734</u>
Management and administration		
Employee expenses	42,847	58,451
Other operating expenses	22,332	17,793
Som der lasten	<u>65,179</u>	<u>76,244</u>
Result	<u>3,624</u>	<u>26,123</u>
Financial income and expenses	511	-91
Balance	<u><u>4,135</u></u>	<u><u>26,032</u></u>

4 FINANCIAL POSITION

The balance sheet can be summarized as follows:

	12/31/2023		12/31/2022	
	€	€	€	€
Long term funds:				
Reserves and funds		116,889		112,757
		<u> </u>		<u> </u>
This amount is applied as follows:				
Receivables, prepayments and accrued income	7,630		10,406	
Cash and cash equivalents	<u>126,556</u>		<u>118,312</u>	
		134,186		128,718
Debit: Short-term debt		<u>17,297</u>		<u>15,961</u>
Working capital		<u>116,889</u>		<u>112,757</u>

Yours sincerely,

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

MANAGEMENT BOARD REPORT

Management Board Report 2023

Stichting World Duchenne Organization, Veenendaal

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, diagnosed with Duchenne and Becker Muscular Dystrophy 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 2023, the organization had 52 member organizations from 39 countries.
For all members see <https://www.worldduchenne.org/wdo-members/>

ACTIVITIES DURING THE YEAR 2023

Besides supporting our members and informing our community about the latest information regarding research and care to our community, the organization was involved in advocacy activities, participation in expert meetings. And executed the programs we have in place such as the Emergency program, the Accredited Duchenne Care Centers Program, Duchenne Care Conference and Duchenne Patient Academy (in collaboration with Duchenne Data Foundation)

We welcomed new [WDO Member](#) and [WDO Aspiring Member](#) organizations. Through the [Duchenne CAB](#), 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](#), the end-of-project [EURO-NMD Registry Hub](#) and [Trials@Home](#). Another key activity is the sharing of [Prof Aartsma-Rus' paper-a-days](#), where she reads and comments on scientific publications.

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 2023 board members of WDO attended meetings of these organisations

In the year of 2023, the World Duchenne Organization organized the following events and activities:

KEY ACTIVITIES: WORLD DUCHENNE ORGANIZATION – 2023
February
Meeting: WDO Member Meeting 2023 Launching documentary 'Help has no borders' part of Duchenne Emergency Program Activated the DMD Emergency Program for families affected by the earthquake in Turkey/Syria Participation ENMC meeting
March
Presented at GetReal conference Participated Share4Rare conference Panel DIA 2023 conference Diamond session on RWE Basel Three Day training in Collaboration with Health-RI FAIR Training Efforts
April
Speaker EMA multi-stakeholder workshop on qualification of novel methodologies
June
Conference: Organize Duchenne Care Conference 2023
September
World Duchenne Awareness Day: Breaking Barriers
October
Launch of the Accredited Duchenne Centers Program
November

[United Nations](#) Officially Designates September 7 as [World Duchenne Awareness Day](#)

Webinar: [Gene therapy for DMD](#) by prof Annemieke Aartsma-Rus

December

Conference: Co-organize [Duchenne Patient Academy 2023](#)

Participate in the 269th ENMC International Workshop on: [Clinical trials in DMD: Ten years on, what have we learned? How can we optimize future trial design?](#)

FINANCIAL STATEMENTS

Stichting World Duchenne Organization, Veenendaal

1 BALANCE SHEET AS AT DECEMBER 31, 2023
(after result appropriation)

		December 31, 2023		December 31, 2022	
		€	€	€	€
ASSETS					
CURRENT ASSETS					
Receivables, prepayments and accrued income	(1)	7,630		10,406	
Cash and cash equivalents	(2)	126,556		118,312	
			134,186		128,718
			134,186		128,718

	December 31, 2023		December 31, 2022	
	€	€	€	€
EQUITY AND LIABILITIES				
RESERVES AND FUNDS (3)				
Allocation reserves	298,604		391,971	
Unrestricted funds, general	<u>-181,715</u>		<u>-279,214</u>	
		116,889		112,757
CURRENT LIABILITIES (4)				
Accounts payable	2,099		-	
Taxes and social securities	917		1,680	
Other liabilities and Accruals and deferred income	<u>14,281</u>		<u>14,281</u>	
		17,297		15,961
		<u>134,186</u>		<u>128,718</u>

2 STATEMENT OF THE FINANCIAL ACCOUNTS OVER 2023

	Balance 2023	Balance 2022
	€	€
Income		
Income from individuals & Legal entities	(5) 90,483	60,552
Subsidies	(6) 142,890	163,549
Sum of income	233,373	224,101
Expenses		
Expenditure on activities	(7) 122,279	91,977
Expenditure on other activities	(8) 42,291	29,757
	164,570	121,734
Management and administration		
Employee expenses	(9) 42,847	58,451
Other operating expenses	(10) 22,332	17,793
	65,179	76,244
Balance before financial income and expense		
Interest and similar income	(11) 3,624	26,123
	511	-91
Result	4,135	26,032
Appropriation of the results		
Allocation reserves	-93,367	89,623
Unrestricted funds, general	97,502	-63,591
	4,135	26,032

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

General

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, 2023

ASSETS

1. Receivables, prepayments and accrued income

	<u>12/31/2023</u>	<u>12/31/2022</u>
	€	€
<i>Accounts receivable</i>		
Accounts receivables	<u>6,817</u>	<u>4,647</u>
 <i>Other receivables and accruals</i>		
Other receivables	<u>813</u>	<u>5,759</u>
 2. Cash and cash equivalents		
ABN Amro NL10ABNA0120254093	431	-
PayPal WCN3VRLEQWUZL	13,939	-
ABN Amro NL91ABNA0417429207	23,399	30,037
ABN Amro NL92ABNA0423265970	<u>88,787</u>	<u>88,275</u>
	<u>126,556</u>	<u>118,312</u>

The liquid resources are valued at nominal value. The liquid resources available as at December 31, 2023 are freely available to the Stichting World Duchenne Organization.

EQUITY AND LIABILITIES

3. Reserves and funds

	12/31/2023	12/31/2022
	€	€
Allocation reserves		
Allocation reserve Share4Rare project	-	46,511
Allocation reserve Trials at Home project	171,131	78,396
Allocation reserve Vision DMD	-	127,134
Allocation reserve BIND	93,456	80,765
Allocation reserve BEAMER	34,017	59,165
	<u>298,604</u>	<u>391,971</u>

	2023	2022
	€	€

Allocation reserve Share4Rare project

Stand per January 1	46,511	46,511
Result allocation	-46,511	-
Carrying amount as of December 31	<u>-</u>	<u>46,511</u>

This is the part of the subsidy received from the European Commission that has not yet been spent on the project Share4Rare.

Allocation reserve Trials at Home project

Stand per January 1	78,396	92,945
Result allocation	92,735	-14,549
Carrying amount as of December 31	<u>171,131</u>	<u>78,396</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 Vision DMD

Stand per January 1	127,134	68,264
Result allocation	-127,134	58,870
Carrying amount as of December 31	<u>-</u>	<u>127,134</u>

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

Allocation reserve BIND

Stand per January 1	80,765	50,393
Result allocation	12,691	30,372
Carrying amount as of December 31	<u>93,456</u>	<u>80,765</u>

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

Stichting World Duchenne Organization, Veenendaal

	2023	2022
	€	€
<i>Allocation reserve BEAMER</i>		
Stand per January 1	59,165	44,235
Result allocation	-25,148	14,930
Carrying amount as of December 31	<u>34,017</u>	<u>59,165</u>

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

Unrestricted funds, general

Carrying amount as of January 1	-279,217	-215,623
Allocation of financial year net result	97,502	-63,591
Carrying amount as of December 31	<u>-181,715</u>	<u>-279,214</u>

4. Current liabilities

	12/31/2023	12/31/2022
	€	€
<i>Accounts payable</i>		
Accounts payable	<u>2,099</u>	<u>-</u>
<i>Taxes and social securities</i>		
Pay-roll tax	<u>917</u>	<u>1,680</u>
<i>Accruals and deferred income</i>		
Other costs	105	105
Current account Duchenne Data Foundation	<u>14,176</u>	<u>14,176</u>
	<u>14,281</u>	<u>14,281</u>

5 NOTES TO THE STATEMENT OF FINANCIAL ACTIVITIES 2023

	Balance 2023	Balance 2022
	€	€
5. Income from individuals & Legal entities		
Membershipfee	31,739	17,078
Donations Facebook	2,244	18,031
Duchenne Patient Academy	14,000	-
Donations Ukraine emergency fund	22,500	25,443
Donations Turkey emergency fund	10,000	-
Donations ADC Data Project	5,000	-
Donations CAB	5,000	-
	<u>90,483</u>	<u>60,552</u>
6. Subsidies		
European Commission subsidy Trials at Home	119,394	25,777
European Commission subsidy Vision DMD	-	58,870
European Commission subsidy BIND	23,496	37,240
European Commission subsidy BEAMER	-	41,662
	<u>142,890</u>	<u>163,549</u>
7. Expenditure on activities		
Expenses Trials at Home	26,659	40,326
Expenses BIND	10,804	6,868
Expenses WDO	2,187	6,324
Expenses WDAD	35,366	11,727
Expenses BEAMER	47,263	26,732
	<u>122,279</u>	<u>91,977</u>
8. Expenditure on other activities		
Expenses Accreditation Duchenne Centers project	30,976	9,757
Expenses Ukraine emergency fund	-	20,000
Expenses Turkey emergency fund	10,000	-
Expenses Empowered Project	1,315	-
	<u>42,291</u>	<u>29,757</u>

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

2023: 70.5 %

2022: 54.3 %

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

2023: 71.6 %

2022: 61.5 %

	Balance 2023	Balance 2022
	€	€
9. Employee expenses		
Wages and salaries	34,062	46,782
Social security charges	5,787	7,883
Other personnel costs	2,998	3,786
	<u>42,847</u>	<u>58,451</u>
<i>Wages and salaries</i>		
Gross wages	31,647	43,317
Gross holidaypay	2,415	3,465
	<u>34,062</u>	<u>46,782</u>
<i>Social security charges</i>		
Other social charges	<u>5,787</u>	<u>7,883</u>
<i>Other personnel costs</i>		
Travelling expenses	1,977	3,578
Education allowance and training costs	1,021	208
	<u>2,998</u>	<u>3,786</u>
Staff		
In 2023 0.4 employees were employed, converted to full-time (2022: 0.8)		
10. Other operating expenses		
Office expenses	13,795	10,381
Publicity expenses	97	400
General expenses	8,440	7,012
	<u>22,332</u>	<u>17,793</u>
<i>Office expenses</i>		
Automation costs	7,133	3,666
Telephone and internet costs	1,204	1,115
Contributions and subscriptions	5,458	5,600
	<u>13,795</u>	<u>10,381</u>
<i>Publicity expenses</i>		
Website costs	<u>97</u>	<u>400</u>
<i>General expenses</i>		
Audit costs	8,571	10,521
Audit costs previous years	-1,398	-5,000
Liability insurance	962	1,059
Banking costs	335	461
Other general expenses	-30	-29
	<u>8,440</u>	<u>7,012</u>

Stichting World Duchenne Organization, Veenendaal

	<u>Balance 2023</u>	<u>Balance 2022</u>
	€	€
11. Interest and similar income		
Bank interest	<u>511</u>	<u>-91</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.