STICHTING WORLD DUCHENNE ORGANIZATION AT VEENENDAAL
Annual Report 2025

August 25, 2026

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AUDITOR'S REPORT

STOLWIJK
ACCOUNTANTS & BELASTINGADVISEURS

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

Reference	*Processed by*	*Date*
11200	HdB/IL	August 25, 2026

Dear members of the Executive Board,

We hereby send you the report regarding the financial statements for the year 2025 of the foundation.

1 ENGAGEMENT

In accordance with your instructions we have compiled the annual account 2025 of the foundation, including the balance sheet with counts of € 225,855 and the profit and loss account with a result of € 294,884.

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, 2025 and the profit and loss account for the year 2025 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 2025 amounts to € 295,000 compared to € 36,000 for 2024. The results for both years can be summarized as follows:

	Saldo 2025	Saldo 2024
	€	€
Income		
Income from individuals & Legal entities	264,025	285,070
Grants	333,113	122,906
Gross margin	597,138	407,976
Expenses		
Expenditure on activities	243,104	203,588
Expenditure on other activities	38,978	84,216
	282,082	287,804
Management and administration		
Employee expenses	-2,780	28,506
Other operating expenses	24,562	57,273
Som der lasten	21,782	85,779
Result	293,274	34,393
Financial income and expenses	1,610	1,323
Balance	294,884	35,716

4 FINANCIAL POSITION

The balance sheet can be summarized as follows:

	12/31/2025		12/31/2024	
	€	€	€	€
Long term funds:				
Reserves and funds		137,652		-157,232
This amount is applied as follows:				
Receivables, prepayments and accrued income	143,862		44,539	
Cash and cash equivalents	81,993		134,740	
		225,855		179,279
Debit: Short-term debt		88,203		336,511
Working capital		137,652		-157,232

Yours sincerely,

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

STOLWIJK
ACCOUNTANTS & BELASTINGADVISEURS

MANAGEMENT BOARD REPORT

WORLD DUCHENNE ORGANIZATION
UPPMD

Management Board Report 2025

Stichting World Duchenne Organization, Veenendaal, The Netherlands

GENERAL
On May 21, 2007 the Stichting World Duchenne organization (former Stichting United Parent Projects Muscular Dystrophy) was officially founded. Stichting World Duchenne Organization (Coe file 30226334) has its registered office in Zeist, The Netherlands.

WDO is an eligible member of the European Medicines Agency, a member of Rare Diseases International, European Patients Forum, Eurordis, and European Neuromuscular Centre (ENMC).

The organization in 2025 had the following BoD:

BOARD MEMBERS
Elizabeth Vroom, Chair
Ed Snitselaar, Treasurer
Patricia Furlong
Sally Hofmeister
Dimitrios Athanasiou
Ialina Vinci
Aida Adra
Graciela Mendez
Karolina Podolska

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 informing 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 practices of the best clinicians from all over the world.

It is equally important that the information available to parents is contemporary, truthful, and based on 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 are utilized.

MEMBERS
In 2025, the organization had 48 full members and 10 aspiring members
For all members see https://www.worldduchenne.org/wdo-members/

WORLD DUCHENNE ORGANIZATION
UPPMD

ACTIVITIES DURING THE YEAR 2025

Besides supporting our members and sending regular updates to our community, the organization was involved in advocacy activities, education of patient experts and clinicians and participated in expert meetings.
With the new Accelerate Duchenne Project and the existing Duchenne Community Advisory Board there is a strong focus to accelerate and optimize drug development for DMD.
The Global Duchenne Care Conference and the Accredited Duchenne Center program optimal care is promoted. Through the Accredited Duchenne Care Centers program, WDO guides patients to centers where care is provided according to the current Standards of Care, and helps centers around the globe to improve the care provided.
The Duchenne Care Conference WDO is annually organized, attracting in 2025 more than 700 HCPs and patient experts from 72 countries around the globe.

We welcomed new WDO Member and WDO Aspiring Member organizations. WDO plays a key role in informing the global community on the different fields important for everybody living with Duchenne MD, such as research updates, the optimal (re) use of health data, implementation of Standards of care, and progress in drug development and access.
WDO organized multiple webinars and online conferences on these topics. WDO participated in several events organized by the European Neuromuscular Center, EURORDIS, the European Medicines Agency and our member organisations.

WDO remains actively involved as a partner in various European-funded projects such as BEAMER, ERDERA, EURO-NMD Registry Hub and others, and was a main contributor in the landmark project Trials@Home. After the BIND EU project ended, World Duchenne Organization took the task to found the BIND association (‘vereniging’ under Dutch law) to continue the impressive work of the BIND.EU consortium.

Through our Emergency program, we are able to support our member organizations in regions of natural disasters and war.

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

In 2023, the United Nations marked a momentous milestone for the global rare disease community by officially designating September 7 as World Duchenne Awareness Day. The adoption of the resolution “World Duchenne Awareness Day” is the UN’s first formal acknowledgment of a day dedicated to a rare disease.
This WDO initiative started in 2013 and has been growing exponentially since then with the support of the European Parliament and the Pope. The special theme of WDAD 2025 was ‘Family, The Heart Of Care.’ The documentary highlighting how love, community, and determination shape life with Duchenne.
In the year 2025, the World Duchenne Organization organized the following events and activities:



WORLD DUCHENNE ORGANIZATION
UPPMD

KEY ACTIVITIES: WORLD DUCHENNE ORGANIZATION – 2025
February
Members meeting, Rome Italy *The Member Meeting brings together WDO members, strengthening education and community building.* *Duchenne Community meeting February 28, 2025 Rome The Global Duchenne Community Meeting, in collaboration with the Duchenne Data Foundation, promotes education on Duchenne at a global level across various topics, including care, drug development, and social aspects.*
April
Organized the Post MDA webinar April 3, 2025 *The Post-MDA Webinar is dedicated to drug development informing our members about the latest information presented at the MDA Conference 2025* **Symposium at Mena Congress 17-20 April, 2025 Abu Dhabi** *The MENA Congress is a major educational event on rare diseases in the Middle East, where WDO coordinated a symposium on Duchenne.*
May
Duchenne Drug Development Round Table May 6, 2025, Rome First meeting of the new Accelerate Duchenne Program: *Roundtable focusing on drug development and regulatory aspects supported by Duchenne Parent Project, The Netherlands.*
June
Global Duchenne Care Conference May 26 and 27, 2025 *The Care Conference is an online event dedicated exclusively to the clinical management of Duchenne, with a global audience (more than 700 participants from 70+ countries)*
September
Organized World Duchenne Awareness Day on September 7th Global activities around the theme of World Duchenne Awareness Day “Family at the heart of care” https://www.youtube.com/watch?v=xoMFtOnuD0s

WORLD DUCHENNE ORGANIZATION
UPPMD

December
Duchenne Patient Academy 2025 *The Duchenne Patient Academy, in collaboration with the Duchenne Data Foundation, aims to educate on drug development, advocacy, and community building. Over 300 Duchenne and Becker MD patient representatives attended.*

STOLWIJK
ACCOUNTANTS & BELASTINGADVISEURS

FINANCIAL STATEMENTS

1 BALANCE SHEET AS AT DECEMBER 31, 2025

(after result appropriation)

		December 31, 2025		December 31, 2024	
		€	€	€	€
ASSETS					
CURRENT ASSETS					
Receivables, prepayments and accrued income	(1)	143,862		44,539	
Cash and cash equivalents	(2)	81,993		134,740	
			225,855		179,279
			225,855		179,279

		December 31, 2025		December 31, 2024	
		€	€	€	€
EQUITY AND LIABILITIES					
RESERVES AND FUNDS	(3)				
Unrestricted funds, general			137,652		-157,232
CURRENT LIABILITIES	(4)				
Accounts payable		4,813		1,246	
Taxes and social securities		11,528		11,253	
Other liabilities and Accruals and deferred income		71,862		324,012	
			88,203		336,511
			225,855		179,279

2 STATEMENT OF THE FINANCIAL ACCOUNTS OVER 2025

		Balance 2025	Balance 2024
		€	€
Income			
Income from individuals & Legal entities	(5)	264,025	285,070
Grants	(6)	333,113	122,906
Sum of income		597,138	407,976
Expenses			
Expenditure on activities	(7)	243,104	203,588
Expenditure on other activities	(8)	38,978	84,216
		282,082	287,804
Management and administration			
Employee expenses	(9)	-2,780	28,506
Other operating expenses	(10)	24,562	57,273
		21,782	85,779
Balance before financial income and expense		293,274	34,393
Interest and similar income	(11)	1,610	1,323
Result		294,884	35,716
Appropriation of the results			
Allocation reserves		-	11,232
Unrestricted funds, general		294,884	24,484
		294,884	35,716

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 providor 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, 2025

ASSETS

1. Receivables, prepayments and accrued income

	12/31/2025	12/31/2024
	€	€
Accounts receivable		
Accounts receivables	141,102	60,539
Doubtful debtor provision	-	-16,000
	141,102	44,539
Overige vorderingen en overlopende activa		
Prepaid expenses BIND	2,411	-
Interest	349	-
	2,760	-

2. Cash and cash equivalents

ABN Amro NL10ABNA0120254093	-	345
PayPal WCN3VRLEQWUZL	14,208	14,793
ABN Amro NL91ABNA0417429207	16,412	29,491
ABN Amro NL92ABNA0423265970	51,373	90,111
	81,993	134,740

The liquid resources are valued at nominal value. The liquid resources available as at December 31, 2025 are freely available to the Stichting World Duchenne Organization.

EQUITY AND LIABILITIES

3. Reserves and funds

Allocation reserves

	2025	2024
	€	€
Unrestricted funds, general		
Carrying amount as of January 1	-157,232	-181,716
Allocation of financial year net result	294,884	24,484
Carrying amount as of December 31	137,652	-157,232

In the original 2024 financial statements, equity amounted to €152,604.
In the 2024 financial statements, received grants that have not yet been spent amounting to € 309,836 were incorrectly recognized as allocation reserve for projects.

The breakdown was as follows:

Allocated Reserves Trails at Home	€ 167.326
Allocated Reserves BIND	€ 69.713
Allocated Reserves BEAM ER	€ 41.523
Allocated Reserves ERDERA	€ 31.274
Unrestricted funds	€ -157.232
Total 31-12-2024	€ 152.604

The received grants that have not yet been spent should have been presented as liabilities relating to subsidies receives but not yet spent. As a result of this error, the comparative figures have been restated in these financial statements. The correction has led to a reclassification between equity and liabilities and has consequently affected the level of equity. The impact of the correction has been reflected in the opening balance of equity and liabilities and the comparative figures have been adjusted accordingly.

4. Current liabilities

	12/31/2025	12/31/2024
	€	€
Accounts payable		
Accounts payable	4,813	1,246
Taxes and social securities		
VAT	11,528	11,253

	12/31/2025	12/31/2024
	€	€
VAT		
VAT fourth quarter	11,317	12,020
VAT third quarter	-	-888
VAT supplement 2025	90	-
VAT supplement 2024	121	121
	11,528	11,253

Accruals and deferred income		
Current account Duchenne Data Foundation	-	14,176
Deferred grant income Trials at Home	-	167,326
Deferred grant income BIND	-	69,713
Deferred grant income BEAMER	53,504	41,523
Deferred grant income ERDERA	18,358	31,274
	71,862	324,012

In the original 2024 financial statements,the accruals and deferred income amounted to € 14.176.

In the 2024 financial statements, received grants that have not yet been spent amounting to € 309,836 were incorrectly recognized as allocation reserve for projects.

The breakdown was as follows:

Allocated Reserves Trails at Home	€ 167.326
Allocated Reserves BIND	€ 69.713
Allocated Reserves BEAM ER	€ 41.523
Allocated Reserves ERDERA	€ 31.274
Total 31-12-2024	€ 309.836

The received grants that have not yet been spent should have been presented as liabilities relating to subsidies receives but not yet spent. As a result of this error, the comparative figures have been restated in these financial statements. The correction has led to a reclassification between equity and liabilities and has consequently affected the level of equity. The impact of the correction has been reflected in the opening balance of equity and liabilities and the comparative figures have been adjusted accordingly.

5 NOTES TO THE STATEMENT OF FINANCIAL ACTIVITIES 2025

	Balance 2025	Balance 2024
	€	€
5. Income from individuals & Legal entities		
Donations and gifts	5,243	1,899
Membershipfee	22,281	18,585
Donations CAB	236,501	264,586
	264,025	285,070
6. Grants		
European Commission grant Trials at Home	38,393	49,610
European Commission grant BIND	20	-
European Commission grant BEAMER	33,776	41,056
European Commission grant ERDERA	12,916	32,240
Release of grants to income	248,008	-
	333,113	122,906
7. Expenditure on activities		
Expenses CAB	112,411	65,668
Expenses Trials at Home	38,393	53,415
Expenses BIND	20	23,743
Expenses WDO	19,409	5,345
Expenses WDAD	17,524	20,901
Expenses BEAMER	33,776	33,550
Expenses ERDERA	12,916	966
Expenses DDDRT	8,655	-
	243,104	203,588
8. Expenditure on other activities		
Expenses Accreditation Duchenne Centers project	21,625	34,234
Expenses conferences, meetings, seminars	17,353	49,982
	38,978	84,216

Het totaal bestedingen aan doelstellingen uitgedrukt in een percentage van de totale baten is:
2025: 47.2 %
2024: 70.5 %

Het totaal bestedingen aan doelstellingen uitgedrukt in een percentage van de totale lasten is:
2025: 92.8 %
2024: 77.0 %

9. Employee expenses		
Wages and salaries	-4,880	15,957
Social security charges	-	5,221
Other personnel costs	2,100	7,328
	-2,780	28,506

	Balance 2025	Balance 2024
	€	€
Wages and salaries		
Gross wages	-	28,021
Gross holidaypay	-	2,150
Sick pay received	-4,880	-14,214
	-4,880	15,957
Social security charges		
Other social charges	-	5,221
Other personnel costs		
Travelling expenses	-	1,985
Education allowance and training costs	-	5,343
Volunteer compensation	2,100	-
	2,100	7,328

Staff

In 2025 no employees were employed, converted to full-time (2024: 0.5)

10. Other operating expenses

Office expenses	12,377	12,398
Publicity expenses	-16,000	16,000
General expenses	28,185	28,875
	24,562	57,273
Office expenses		
Automation costs	5,790	5,316
Telephone and internet costs	1,037	1,324
Contributions and subscriptions	5,550	5,758
	12,377	12,398
Publicity expenses		
Allocation to accrual doubtfull debtors	-16,000	16,000
General expenses		
Audit costs	7,185	6,892
Advice fees	1,800	-
Liability insurance	962	962
Tax authority fines	-	100
Banking costs	648	1,009
Non-deductible VAT	17,566	19,754
Other general expenses	24	158
	28,185	28,875

Financial income and expenses

	Balance 2025	Balance 2024
	€	€
11. *Interest and similar income*		
Bank interest	1,610	1,323

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	68.000	
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	78.710	16.529
5: Voorbelasting en kleineondernemersregeling		
5a: Verschuldigde omzetbelasting		16.529
5b: Voorbelasting		-2.929
Saldo eerder opgegeven		-13.510
Te betalen omzetbelasting		**90**

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