

**STICHTING WORLD DUCHENNE ORGANIZATION
AT VEENENDAAL**
Annual Report 2022

December 18, 2023

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AUDITOR'S REPORT

To the board of

<i>Reference</i>	<i>Processed by</i>	<i>Date</i>
11200	HB/IL	December 18, 2023

Dear members of the Executive Board,

We hereby send you the report regarding the financial statements for the year 2022 of the foundation.

1 ENGAGEMENT

In accordance with your instructions we have compiled the annual account 2022 of the foundation, including the balance sheet with counts of € 128,718 and the profit and loss account with a result of € 26,032.

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, 2022 and the profit and loss account for the year 2022 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.

2.1 Recognition of the 2021 loss

The result amounting to € 43,102 has been carried forward as accumulated deficit.

3 RESULTS

3.1 Comparative overview

The result for 2022 amounts to € 26,000 compared to negative € 43,000 for 2021. The results for both years can be summarized as follows:

	Saldo 2022	Saldo 2021
	€	€
Income		
Income from individuals & Legal entities	60,552	36,310
Subsidies	163,549	114,195
Gross margin	<u>224,101</u>	<u>150,505</u>
Expenses		
Expenditure on activities	91,977	103,525
Expenditure on other activities	29,757	-
	<u>121,734</u>	<u>103,525</u>
Management and administration		
Employee expenses	58,451	58,871
Other operating expenses	17,793	31,211
Som der lasten	<u>76,244</u>	<u>90,082</u>
Result	<u>26,123</u>	<u>-43,102</u>
Financial income and expenses	-91	-
Balance	<u><u>26,032</u></u>	<u><u>-43,102</u></u>

4 FINANCIAL POSITION

The balance sheet can be summarized as follows:

	12/31/2022		12/31/2021	
	€	€	€	€
Long term funds:				
Reserves and funds		112,757		86,725
		<u> </u>		<u> </u>
This amount is applied as follows:				
Receivables, prepayments and accrued income	10,406		5,489	
Cash and cash equivalents	<u>118,312</u>		<u>116,808</u>	
		128,718		122,297
Debit: Short-term debt		15,961		35,572
		<u> </u>		<u> </u>
Working capital		<u>112,757</u>		<u>86,725</u>

Yours sincerely,

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

MANAGEMENT BOARD REPORT



**WORLD
DUCHENNE
ORGANIZATION**
UPPMD

Management Board Report 2022

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 organization in 2022

BOARD MEMBERS

Elizabeth Vroom, chair
Ed Snitselaar, treasurer
Patricia Furlong
Sally Hofmeister
Dimitrios Athanasiou
Santiago Ordoñez

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 2022, the organization had 52 member organizations from 39 countries.

For all members see <https://www.worldduchenne.org/wdo-members/>

ACTIVITIES DURING THE YEAR 2021

Besides supporting our members and sending regular updates to our community, the organization was involved in advocacy activities, participation in expert meetings.

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](#), [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. In the year of 2022, the World Duchenne Organization organized the following events and activities:

KEY ACTIVITIES: WORLD DUCHENNE ORGANIZATION – 2022
February
Meeting: WDO Member Meeting 2022
March
Activate the DMD Emergency Program for families affected by the war in Ukraine
May
Participation: 263th ENMC International Workshop on: Focus on female carriers of dystrophinopathy: refining recommendations for prevention, diagnosis, surveillance and treatment.
June
Conference: Organize the Duchenne Care Conference 2022 on Adult Duchenne Care
Organize various webinars for the BIND project
September
Conference: World Duchenne Awareness Day: Women & Duchenne
Award the World Duchenne Organization Leadership Award to Professor Muntoni
Participation: Stakeholder Workshop and meeting at EMA on Decentralized Clinical Trials
October
Launch of the Accredited Duchenne Centers Program
November

Conference: [3rd International Muscle-Bone Interaction in Duchenne Muscular Dystrophy Symposium](#)

Training: Organize the [3rd International FAIR data 'visiting' for Duchenne & Other Rare Diseases](#)

December

Conference: [Co-organize Duchenne Patient Academy 2022](#)

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

1 BALANCE SHEET AS AT DECEMBER 31, 2022
(after result appropriation)

		December 31, 2022		December 31, 2021	
		€	€	€	€
ACTIVA					
CURRENT ASSETS					
Receivables, prepayments and accrued income	(1)	10,406		5,489	
Cash and cash equivalents	(2)	118,312		116,808	
			128,718		122,297
				128,718	122,297

	December 31, 2022		December 31, 2021	
	€	€	€	€
PASSIVA				
RESERVES AND FUNDS	(3)			
Allocation reserves	391,971		302,348	
Unrestricted funds, general	<u>-279,214</u>		<u>-215,623</u>	
		112,757		86,725
CURRENT LIABILITIES	(4)			
Accounts payable	-		14,848	
Taxes and social securities	1,680		1,548	
Other liabilities and Accruals and deferred income	<u>14,281</u>		<u>19,176</u>	
		15,961		35,572
		<u>128,718</u>		<u>122,297</u>

2 STATEMENT OF THE FINANCIAL ACCOUNTS OVER 2022

	Balance 2022	Balance 2021
	€	€
Income		
Income from individuals & Legal entities	(5) 60,552	36,310
Subsidies	(6) 163,549	114,195
Sum of income	224,101	150,505
Expenses		
Expenditure on activities	(7) 91,977	103,525
Expenditure on other activities	(8) 29,757	-
	121,734	103,525
Management and administration		
Employee expenses	(9) 58,451	58,871
Other operating expenses	(10) 17,793	31,211
	76,244	90,082
Balance before financial income and expense	26,123	-43,102
Interest and similar expenses	(11) -91	-
Result	26,032	-43,102
Appropriation of the results		
Allocation reserves	89,623	36,310
Unrestricted funds, general	-63,591	-79,412
	26,032	-43,102

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.

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.

Currency translation differences

Currency translation differences arising upon the settlement or conversion of monetary items are recognised in the income statement in the period that they are realised, unless hedge accounting is applied.

Dividends

Dividends to be received from participations and securities not carried at net asset value are recognised as soon as Stichting World Duchenne Organization has acquired the right to them.

Changes in value of financial instruments recognised at fair value

Changes in value of financial instruments recognised at vurrent value are taken to the profit and loss account.

4 NOTES TO THE BALANCE SHEET AS OF DECEMBER 31, 2022

ASSETS

1. Receivables, prepayments and accrued income

	<u>12/31/2022</u>	<u>12/31/2021</u>
	€	€
<i>Accounts receivable</i>		
Accounts receivables	<u>4,647</u>	<u>5,350</u>
 <i>Other receivables and accruals</i>		
Other receivables	<u>5,759</u>	<u>139</u>
 2. Cash and cash equivalents		
ABN Amro NL91ABNA0417429207	30,037	18,533
ABN Amro NL92ABNA0423265970	<u>88,275</u>	<u>98,275</u>
	<u>118,312</u>	<u>116,808</u>

The liquid resources are valued at nominal value. The liquid resources available as at December 31, 2022 are freely available to the Stichting World Duchenne Organization.

EQUITY AND LIABILITIES

3. Reserves and funds

	12/31/2022	12/31/2021
	€	€
Allocation reserves		
Allocation reserve Share4Rare project	46,511	46,511
Allocation reserve Trials at Home project	78,396	92,945
Allocation reserve Vision DMD	127,134	68,264
Allocation reserve BIND	80,765	50,393
Allocation reserve BEAMER	59,165	44,235
	<u>391,971</u>	<u>302,348</u>

	2022	2021
	€	€

Allocation reserve Share4Rare project

Stand per January 1	46,511	51,256
Result allocation	-	-4,745
Carrying amount as of December 31	<u>46,511</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	92,945	87,928
Result allocation	-14,549	5,017
Carrying amount as of December 31	<u>78,396</u>	<u>92,945</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	68,264	57,906
Result allocation	58,870	10,358
Carrying amount as of December 31	<u>127,134</u>	<u>68,264</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	50,393	68,948
Result allocation	30,372	-18,555
Carrying amount as of December 31	<u>80,765</u>	<u>50,393</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

	2022	2021
	€	€
<i>Allocation reserve BEAMER</i>		
Stand per January 1	44,235	-
Result allocation	14,930	44,235
Carrying amount as of December 31	<u>59,165</u>	<u>44,235</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	-215,623	-136,211
Allocation of financial year nett result	-63,591	-79,412
Carrying amount as of December 31	<u>-279,214</u>	<u>-215,623</u>

4. Current liabilities

	12/31/2022	12/31/2021
	€	€
<i>Accounts payable</i>		
Accounts payable	-	14,848
<i>Taxes and social securities</i>		
Pay-roll tax	<u>1,680</u>	<u>1,548</u>
<i>Accruals and deferred income</i>		
Audit costs	-	5,000
Other costs	105	-
Current account Duchenne Data Foundation	14,176	14,176
	<u>14,281</u>	<u>19,176</u>

5 NOTES TO THE STATEMENT OF FINANCIAL ACTIVITIES 2022

	Balance 2022	Balance 2021
	€	€
5. Income from individuals & Legal entities		
Membershipfee	17,078	19,473
Donations Facebook	18,031	2,837
Duchenne Patient Academy	-	14,000
Donations Ukraine emergency fund	25,443	-
	<u>60,552</u>	<u>36,310</u>
6. Subsidies		
European Commission subsidy Share 4 Rare	-	4,557
European Commission subsidy Trials at Home	25,777	36,893
European Commission subsidy Vision DMD	58,870	16,800
European Commission subsidy BIND	37,240	-
European Commission subsidy BEAMER	41,662	55,945
	<u>163,549</u>	<u>114,195</u>
7. Expenditure on activities		
Expenses Share 4 Rare	-	9,302
Expenses Vision DMD	-	5,642
Expenses Trials at Home	40,326	31,876
Expenses BIND	6,868	18,555
Expenses WDO	6,324	10,965
Expenses WDAD	11,727	15,475
Expenses BEAMER	26,732	11,710
	<u>91,977</u>	<u>103,525</u>
8. Expenditure on other activities		
Expenses Accreditation Duchenne Centers project	9,757	-
Expenses Ukraine emergency fund	20,000	-
	<u>29,757</u>	<u>-</u>
9. Employee expenses		
Wages and salaries	46,782	46,973
Social security charges	7,883	8,320
Other personnel costs	3,786	3,578
	<u>58,451</u>	<u>58,871</u>
<i>Wages and salaries</i>		
Gross wages	43,317	43,519
Gross holidaypay	3,465	3,454
	<u>46,782</u>	<u>46,973</u>

Stichting World Duchenne Organization, Veenendaal

	Balance 2022	Balance 2021
	€	€
<i>Social security charges</i>		
Other social charges	7,883	8,320
<i>Other personnel costs</i>		
Travelling expenses	3,578	3,578
Education allowance and training costs	208	-
	<u>3,786</u>	<u>3,578</u>
Staff		
In 2022 0.8 employees were employed, converted to full-time (2021: 0.7)		
10. Other operating expenses		
Office expenses	10,381	5,809
Publicity expenses	400	5,395
General expenses	7,012	20,007
	<u>17,793</u>	<u>31,211</u>
<i>Office expenses</i>		
Automation costs	3,666	4,285
Telephone and internet costs	1,115	1,074
Contributions and subscriptions	5,600	450
	<u>10,381</u>	<u>5,809</u>
<i>Publicity expenses</i>		
Publicity and advertisement	-	4,900
Website costs	400	495
	<u>400</u>	<u>5,395</u>
<i>General expenses</i>		
Audit costs	10,521	15,484
Audit costs previous years	-5,000	-
Liability insurance	1,059	865
Banking costs	461	400
Amortisation of doubtful debtors	-	3,208
Other general expenses	-29	50
	<u>7,012</u>	<u>20,007</u>
11. Interest and similar expenses		
Interest payable	-91	-

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.