

**STICHTING WORLD DUCHENNE ORGANIZATION  
AT VEENENDAAL**  
Annual Report 2021

December 6, 2022

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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 6, 2022

Dear members of the Executive Board,

We hereby send you the report regarding the financial statements for the year 2021 of the foundation.

## **1 ENGAGEMENT**

In accordance with your instructions we have compiled the annual account 2021 of the foundation, including the balance sheet with counts of € 122,297 and the profit and loss account with a negative result of € 43,102.

## **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, 2021 and the profit and loss account for the year 2021 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](http://www.nba.nl/uitleg-samenstellingsverklaring).

**Stichting World Duchenne Organization, Veenendaal**

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**2.1 Recognition of the 2020 loss**

The result amounting to € 3,186 has been carried forward as accumulated deficit.

**Stichting World Duchenne Organization, Veenendaal**


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**3 RESULTS**
**3.1 Comparative overview**

The result for 2021 amounts to negative € 43,000 compared to negative € 3,000 for 2020. The results for both years can be summarized as follows:

	<u>Saldo 2021</u>	<u>Saldo 2020</u>
	€	€
<b>Income</b>		
Income from individuals & Legal entities	36,310	24,276
Subsidies	<u>114,195</u>	<u>159,448</u>
<b>Gross margin</b>	150,505	183,724
<b>Expenses</b>		
Expenditure on activities	103,525	98,471
<b>Management and administration</b>	90,082	88,444
Financial income and expenses	<u>-</u>	<u>-5</u>
<b>Balance</b>	<u><u>-43,102</u></u>	<u><u>-3,186</u></u>

**Stichting World Duchenne Organization, Veenendaal**

**4 FINANCIAL POSITION**

The balance sheet can be summarized as follows:

	12/31/2021		12/31/2020	
	€	€	€	€
<b>Long term funds:</b>				
Reserves and funds		86,725		129,828
		<u>          </u>		<u>          </u>
This amount is applied as follows:				
Receivables, prepayments and accrued income	5,489		4,550	
Cash and cash equivalents	<u>116,808</u>		<u>133,271</u>	
		122,297		137,821
Debit: Short-term debt		35,572		7,993
		<u>          </u>		<u>          </u>
Working capital		<u>86,725</u>		<u>129,828</u>

Yours sincerely,

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

## **MANAGEMENT BOARD REPORT**





# Management Board Report 2021

*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 UPPMD (Coe file 30226334) has its registered office in Zeist.

*The organization in 2021*

## **BOARD MEMBERS**

Elizabeth Vroom, chair

Ed Snitselaar, treasurer

Patricia Furlong

Sally Hofmeister

Dimitrios Athanasiou

Santiago Ordoñez

## **MISSION AND VISION**

The World Duchenne Organization UPPMD, 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 global. 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 2021, the organization had 47 member organizations from 38 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. Our board members presented on a series of international conferences such as European Patients' Forum and ECRD on topics such as policy, regulations, drug development, research, data and care.

In the year of 2021, the World Duchenne Organization organized the following events and activities:

<b>ACTIVITIES: WORLD DUCHENNE ORGANIZATION – 2021</b>
<b>February</b>
Meeting: WDO Member Meeting 2021
Webinar: <a href="#">Duchenne &amp; Vaccines</a>
<b>March</b>
Meeting: <a href="#">FAIR data visiting in Duchenne</a>
Presentation: <a href="#">2nd International Conference on Rare Diseases: Greek Chapter</a>
<b>June</b>
Conference: <a href="#">Duchenne Care Conference 2021</a>
Event: <a href="#">Share4Rare End Event</a>
<b>July</b>
Meeting: <a href="#">Use of Wearables, and Other Digital Outcome Measures in DMD / BMD</a>
<b>September</b>
Conference: World Duchenne Awareness Day livestream <a href="#">Adult Life and Duchenne</a>
<b>October</b>
Presentation: <a href="#">European Patients' Forum Congress 2021</a>
Presentation: <a href="#">KNAW-advies: Patient perspective in medicine development (NL)</a>
<b>December</b>
Conference: Co-organize <a href="#">Duchenne Patient Academy 2021</a>
Event: <a href="#">VISION-DMD End Event</a>

## **FINANCIAL STATEMENTS**



	December 31, 2021		December 31, 2020	
	€	€	€	€
<b>PASSIVA</b>				
<b>RESERVES AND FUNDS</b>	(3)			
Allocation reserves	302,348		266,038	
Unrestricted funds, general	<u>-215,623</u>		<u>-136,210</u>	
		86,725		129,828
<b>CURRENT LIABILITIES</b>	(4)			
Accounts payable	14,848		-	
Taxes and social securities	1,548		874	
Other liabilities and Accruals and deferred income	<u>19,176</u>		<u>7,119</u>	
		35,572		7,993
		<u>122,297</u>		<u>137,821</u>

**2 STATEMENT OF THE FINANCIAL ACCOUNTS OVER 2021**

	Balance 2021	Balance 2020
	€	€
<b>Income</b>		
Income from individuals & Legal entities	(5) 36,310	24,276
Subsidies	(6) 114,195	159,448
<b>Sum of income</b>	150,505	183,724
<b>Expenses</b>		
Expenditure on activities	(7) 103,525	98,471
<b>Management and administration</b>		
Employee expenses	(8) 58,871	67,946
Other operating expenses	(9) 31,211	20,498
	90,082	88,444
<b>Balance before financial income and expense</b>	-43,102	-3,191
Interest and similar income	(10) -	5
<b>Result</b>	-43,102	-3,186
<b>Appropriation of the results</b>		
Allocation reserves	36,310	78,690
Unrestricted funds, general	-79,412	-81,876
	-43,102	-3,186

### **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 financial statements are drawn up in accordance with the generally accepted accounting principles in the Netherlands.

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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.



**Stichting World Duchenne Organization, Veenendaal**

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***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.

## Stichting World Duchenne Organization, Veenendaal

**4 NOTES TO THE BALANCE SHEET AS OF DECEMBER 31, 2021****ASSETS****1. Receivables, prepayments and accrued income**

	<u>12/31/2021</u>	<u>12/31/2020</u>
	€	€
<i>Accounts receivable</i>		
Accounts receivables	<u>5,350</u>	<u>4,550</u>
 <i>Other receivables and accruals</i>		
Other receivables	<u>139</u>	<u>-</u>
 <b>2. Cash and cash equivalents</b>		
ABN Amro NL91ABNA0417429207	18,533	24,996
ABN Amro NL92ABNA0423265970	<u>98,275</u>	<u>108,275</u>
	<u>116,808</u>	<u>133,271</u>

The liquid resources are valued at nominal value. The liquid resources available as at December 31, 2021 are freely available to the Stichting World Duchenne Organization.

## Stichting World Duchenne Organization, Veenendaal

**EQUITY AND LIABILITIES**
**3. Reserves and funds**

	12/31/2021	12/31/2020
	€	€
<b>Allocation reserves</b>		
Allocation reserve Share4Rare project	46,511	51,256
Allocation reserve Trials at Home project	92,945	87,928
Allocation reserve Vision DMD	68,264	57,906
Allocation reserve BIND	50,393	68,948
Allocation reserve BEAMER	44,235	-
	<u>302,348</u>	<u>266,038</u>

	2021	2020
	€	€

Allocation reserve Share4Rare project

Stand per January 1	51,256	76,100
Result allocation	-4,745	-24,844
Carrying amount as of December 31	<u>46,511</u>	<u>51,256</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	87,928	111,248
Result allocation	5,017	-23,320
Carrying amount as of December 31	<u>92,945</u>	<u>87,928</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	57,906	-
Result allocation	10,358	57,906
Carrying amount as of December 31	<u>68,264</u>	<u>57,906</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	68,948	-
Result allocation	-18,555	68,948
Carrying amount as of December 31	<u>50,393</u>	<u>68,948</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**

	2021	2020
	€	€
<i>Allocation reserve BEAMER</i>		
Stand per January 1	-	-
Result allocation	44,235	-
Carrying amount as of December 31	<u>44,235</u>	<u>-</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	-136,211	-54,334
Allocation of financial year nett result	-79,412	-81,876
Carrying amount as of December 31	<u>-215,623</u>	<u>-136,210</u>

**4. Current liabilities**

	12/31/2021	12/31/2020
	€	€
<i>Accounts payable</i>		
Accounts payable	<u>14,848</u>	<u>-</u>
<i>Taxes and social securities</i>		
Pay-roll tax	<u>1,548</u>	<u>874</u>
<i>Accruals and deferred income</i>		
Audit costs	5,000	7,207
Current account Duchenne Data Foundation	14,176	-88
	<u>19,176</u>	<u>7,119</u>

## Stichting World Duchenne Organization, Veenendaal

**5 NOTES TO THE STATEMENT OF FINANCIAL ACTIVITIES 2021**

	Balance 2021	Balance 2020
	€	€
<b>5. Income from individuals &amp; Legal entities</b>		
Membershipfee	19,473	17,907
Donations Facebook	2,837	6,369
Duchenne Patient Academy	14,000	-
	<u>36,310</u>	<u>24,276</u>
<b>6. Subsidies</b>		
European Commission subsidy Share 4 Rare	4,557	-
European Commission subsidy Trials at Home	36,893	-
European Commission subsidy Vision DMD	16,800	79,366
European Commission subsidy BIND	-	80,082
European Commission subsidy BEAMER	55,945	-
	<u>114,195</u>	<u>159,448</u>
<b>7. Expenditure on activities</b>		
Expenses Share 4 Rare	9,302	24,844
Expenses Vision DMD	5,642	21,460
Expenses Trials at Home	31,876	23,320
Expenses BIND	18,555	11,134
Expenses WDO	10,965	340
Expenses WDAD	15,475	2,812
Expenses Meetings	-	14,561
Expenses BEAMER	11,710	-
	<u>103,525</u>	<u>98,471</u>
<b>8. Employee expenses</b>		
Wages and salaries	46,973	54,046
Social security charges	8,320	10,322
Other personnel costs	3,578	3,578
	<u>58,871</u>	<u>67,946</u>
<i>Wages and salaries</i>		
Gross wages	43,519	50,043
Gross holidaypay	3,454	4,003
	<u>46,973</u>	<u>54,046</u>
<i>Social security charges</i>		
Other social charges	<u>8,320</u>	<u>10,322</u>
<i>Other personnel costs</i>		
Travelling expenses	<u>3,578</u>	<u>3,578</u>

**Stichting World Duchenne Organization, Veenendaal**
**Staff**

In 2021 0.7 employees were employed, converted to full-time (2020: 1.2)

	Balance 2021	Balance 2020
	€	€
<b>9. Other operating expenses</b>		
Office expenses	5,809	2,426
Publicity expenses	5,395	1,015
General expenses	20,007	17,057
	<u>31,211</u>	<u>20,498</u>
<i>Office expenses</i>		
Automation costs	4,285	962
Telephone and internet costs	1,074	1,014
Contributions and subscriptions	450	450
	<u>5,809</u>	<u>2,426</u>
<i>Publicity expenses</i>		
Publicity and advertisement	4,900	-
Website costs	495	1,015
	<u>5,395</u>	<u>1,015</u>
<i>General expenses</i>		
Audit costs	15,484	15,894
Liability insurance	865	962
Banking costs	400	236
Amortisation of doubtful debtors	3,208	-
Other general expenses	50	-35
	<u>20,007</u>	<u>17,057</u>
<b>10. Interest and similar income</b>		
Bank interest	<u>-</u>	<u>5</u>

## **OTHER INFORMATION**

**Stichting World Duchenne Organization, Veenendaal**

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**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.