

**STICHTING UNITED PARENT PROJECT MUSCULAR
DYSTROPHY
AT VEENENDAAL**
Annual Report 2020

January 5, 2022

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AUDITOR'S REPORT

To the board of
Stichting United Parent Project Muscular
Dystrophy
Landjuweel 16-8
3905 PG Veenendaal

<i>Reference</i>	<i>Processed by</i>	<i>Date</i>
11200	HB/IL	January 5, 2022

Dear members of the Executive Board,

We hereby send you the report regarding the financial statements for the year 2020 of the foundation .

1 ENGAGEMENT

In accordance with your instructions we have compiled the annual account 2020 of the foundation, including the balance sheet with counts of € 137,909 and the profit and loss account with a negative result of € 3,186.

2 ACCOUNTANT'S COMPILATION REPORT

To: the management

The financial statements of Stichting United Parent Project Muscular Dystrophy at Veenendaal have been compiled by us using the information provided by you . The financial statements comprise the balance sheet as at December 31, 2020 and the profit and loss account for the year 2020 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 United Parent Project Muscular Dystrophy. 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.

Stichting United Parent Project Muscular Dystrophy, Veenendaal

2.1 Recognition of the 2019 loss

The result amounting to € 26,786 has been carried forward as accumulated deficit.

Stichting United Parent Project Muscular Dystrophy, Veenendaal
3 RESULTS
3.1 Comparative overview

The result for 2020 amounts to negative € 3,000 compared to negative € 27,000 for 2019. The results for both years can be summarized as follows:

	<u>Saldo 2020</u>	<u>Saldo 2019</u>
	€	€
Income		
Income from individuals & Legal entities	24,276	23,418
Subsidies	<u>159,448</u>	<u>145,580</u>
Gross margin	183,724	168,998
Expenses		
Expenditure on activities	98,471	179,256
Management and administration	88,444	16,572
Financial income and expenses	<u>-5</u>	<u>-44</u>
Balance	<u><u>-3,186</u></u>	<u><u>-26,786</u></u>

Stichting United Parent Project Muscular Dystrophy, Veenendaal
4 FINANCIAL POSITION

The balance sheet can be summarized as follows:

	12/31/2020		12/31/2019	
	€	€	€	€
Long term funds:				
Reserves and funds		129,828		133,014
		<u> </u>		<u> </u>
This amount is applied as follows:				
Receivables, prepayments and accrued income	4,638		6,205	
Cash and cash equivalents	<u>133,271</u>		<u>129,761</u>	
		137,909		135,966
Debit: Short-term debt		8,081		2,952
		<u> </u>		<u> </u>
Working capital		<u>129,828</u>		<u>133,014</u>

Stichting United Parent Project Muscular Dystrophy, Veenendaal

Yours sincerely,

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

FINANCIAL REPORT



Management Board Report 2020

*Stichting United Parent Projects Muscular Dystrophy (UPPMD), Veenendaal
World Duchenne Organization*

GENERAL

On May 21, 2007 the Stichting United Parent Project muscular Dystrophy was officially founded. Stichting UPPMD (Coe file 30226334) has its registered office in Zeist.

The organization in 2020

BOARD MEMBERS

Elizabeth Vroom, chair
Ed Snitselaar, treasurer
Patricia Furlong
Sally Hofmeister
Alex Johnson
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 2020, the organization had 45 member organizations from 37 countries and all continents.
For all members see <https://www.worldduchenne.org/members/>

ACTIVITIES DURING THE YEAR 2020

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 DIA and ECRD on topics like policy, regulations, drug development, research, data and care.

- WDO Member Meeting (virtual, February)
- 6 WDO Webinars on [COVID-19 and Duchenne](#)
- World Duchenne Awareness Day livestream on [Duchenne and the Brain](#)
- Co-organise [Duchenne Patient Academy](#)
- Involving the global community in EU projects (e.g. [BIND](#), [Share4Rare](#))
- Pushing for [FAIR data sharing](#) in Duchenne

FINANCIAL STATEMENTS

Stichting United Parent Project Muscular Dystrophy, Veenendaal

1 BALANCE SHEET AS AT DECEMBER 31, 2020

(after result appropriation)

		December 31, 2020		December 31, 2019	
		€	€	€	€
ACTIVA					
CURRENT ASSETS					
Receivables, prepayments and accrued income	(1)	4,638		6,205	
Cash and cash equivalents	(2)	<u>133,271</u>		<u>129,761</u>	
			137,909		135,966
			<u>137,909</u>		<u>135,966</u>

Stichting United Parent Project Muscular Dystrophy, Veenendaal

2 STATEMENT OF THE FINANCIAL ACCOUNTS OVER 2020

	Balance 2020	Balance 2019
	€	€
Income		
Income from individuals & Legal entities	(5) 24,276	23,418
Subsidies	(6) 159,448	145,580
Sum of income	183,724	168,998
Expenses		
Expenditure on activities	(7) 98,471	179,256
Management and administration		
Employee expenses	(8) 67,946	-
Other operating expenses	(9) 20,498	16,572
	88,444	16,572
Balance before financial income and expense	-3,191	-26,830
Interest and similar income	(10) 5	44
Result	-3,186	-26,786
Appropriation of the results		
Allocation reserves	78,690	187,348
Unrestricted funds, general	-81,876	-214,134
	-3,186	-26,786

3 NOTES TO THE BALANCE SHEET AND INCOME STATEMENT

3.1 GENERAL NOTES

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

The registered and actual address of Stichting United Parent Project Muscular Dystrophy (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 United Parent Project Muscular Dystrophy 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.

3.2 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.

3.3 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.

3.4 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 United Parent Project Muscular Dystrophy, Veenendaal

Dividends

Dividends to be received from participations and securities not carried at net asset value are recognised as soon as Stichting United Parent Project Muscular Dystrophy 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.

3.5 NOTES TO THE BALANCE SHEET AS OF DECEMBER 31, 2020
ASSETS
1. Receivables, prepayments and accrued income

	<u>12/31/2020</u>	<u>12/31/2019</u>
	€	€
<i>Accounts receivable</i>		
Accounts receivables	<u>4,550</u>	<u>6,205</u>
 <i>Overige vorderingen en overlopende activa</i>		
Other receivables	<u>88</u>	<u>-</u>
 2. Cash and cash equivalents		
ABN Amro NL91ABNA0417429207	24,996	57,074
ABN Amro NL92ABNA0423265970	<u>108,275</u>	<u>72,687</u>
	<u>133,271</u>	<u>129,761</u>

The liquid resources are valued at nominal value. The liquid resources available as at December 31, 2020 are freely available to the Stichting United Parent Projects Muscular Dystrophy.

Stichting United Parent Project Muscular Dystrophy, Veenendaal

EQUITY AND LIABILITIES

3. Reserves and funds

	12/31/2020	12/31/2019
	€	€
Allocation reserves		
Allocation reserve Share4Rare project	51,256	76,100
Allocation reserve Trials at Home project	87,928	111,248
Allocation reserve Vision DMD	57,906	-
Allocation reserve BIND	68,948	-
	<u>266,038</u>	<u>187,348</u>

	2020	2019
	€	€

Allocation reserve Share4Rare project

Stand per January 1	76,100	-
Result allocation	-24,844	76,100
Carrying amount as of December 31	<u>51,256</u>	<u>76,100</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	111,248	-
Result allocation	-23,320	111,248
Carrying amount as of December 31	<u>87,928</u>	<u>111,248</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	-	-
Result allocation	57,906	-
Carrying amount as of December 31	<u>57,906</u>	<u>-</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	-	-
Result allocation	68,948	-
Carrying amount as of December 31	<u>68,948</u>	<u>-</u>

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

Stichting United Parent Project Muscular Dystrophy, Veenendaal

	<u>2020</u>	<u>2019</u>
	€	€
<i>Unrestricted funds, general</i>		
Carrying amount as of January 1	-54,334	159,800
Allocation of financial year nett result	<u>-81,876</u>	<u>-214,134</u>
Carrying amount as of December 31	<u><u>-136,210</u></u>	<u><u>-54,334</u></u>

4. Current liabilities

	<u>12/31/2020</u>	<u>12/31/2019</u>
	€	€
<i>Accounts payable</i>		
Accounts payable	<u>-</u>	<u>952</u>
<i>Taxes and social securities</i>		
Pay-roll tax	<u>874</u>	<u>-</u>
<i>Accruals and deferred income</i>		
Audit costs	<u>7,207</u>	<u>2,000</u>

Stichting United Parent Project Muscular Dystrophy, Veenendaal

3.6 NOTES TO THE STATEMENT OF FINANCIAL ACTIVITIES 2020

	Balance 2020	Balance 2019
	€	€
5. Income from individuals & Legal entities		
Membershipfee	17,907	20,759
Donations Facebook	6,369	2,659
	<u>24,276</u>	<u>23,418</u>
6. Subsidies		
European Commission subsidy Share 4 Rare	-	20,850
European Commission subsidy Trials at Home	-	124,730
European Commission subsidy Vision DMD	79,366	-
European Commission subsidy BIND	80,082	-
	<u>159,448</u>	<u>145,580</u>
7. Expenditure on activities		
Expenses Share 4 Rare	24,844	51,716
Expenses Vision DMD	21,460	70,260
Expenses Trials at Home	23,320	13,483
Expenses BIND	11,134	-
Expenses WDO	340	28,596
Expenses WDAD	2,812	3,734
Expenses Meetings	14,561	11,467
	<u>98,471</u>	<u>179,256</u>
8. Employee expenses		
Wages and salaries	54,046	-
Social security charges	10,322	-
Other personnel costs	3,578	-
	<u>67,946</u>	<u>-</u>
<i>Wages and salaries</i>		
Gross wages	50,043	-
Gross holidaypay	4,003	-
	<u>54,046</u>	<u>-</u>
<i>Social security charges</i>		
Other social charges	10,322	-
	<u>10,322</u>	<u>-</u>
<i>Other personnel costs</i>		
Travelling expenses	3,578	-
	<u>3,578</u>	<u>-</u>

Staff

In 2020 1.2 employees were employed, converted to full-time (2019: 0)

Stichting United Parent Project Muscular Dystrophy, Veenendaal

	Balance 2020	Balance 2019
	€	€
9. Other operating expenses		
Office expenses	2,426	1,630
Publicity expenses	1,015	1,184
General expenses	17,057	13,758
	<u>20,498</u>	<u>16,572</u>
<i>Office expenses</i>		
Automation costs	962	101
Telephone and internet costs	1,014	1,029
Contributions and subscriptions	450	500
	<u>2,426</u>	<u>1,630</u>
<i>Publicity expenses</i>		
Gifts	-	55
Website costs	1,015	1,129
	<u>1,015</u>	<u>1,184</u>
<i>General expenses</i>		
Audit costs	15,894	12,548
Liability insurance	962	962
Banking costs	236	248
Other general expenses	-35	-
	<u>17,057</u>	<u>13,758</u>
10. Interest and similar income		
Bank interest	<u>5</u>	<u>44</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.