

**STICHTING UNITED PARENT PROJECTS MUSCULAR
DYSTROPHY
AT VEENENDAAL**
Annual Report 2019

February 11, 2021

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AUDITOR'S REPORT

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

<i>Reference</i>	<i>Processed by</i>	<i>Date</i>
11200	HB/IL	February 11, 2021

Dear members of the Executive Board,

We hereby send you the report regarding the financial statements for the year 2019 of the foundation .

1 ENGAGEMENT

In accordance with your instructions we have compiled the annual account 2019 of the foundation, including the balance sheet with counts of € 135,966 and the profit and loss account with a negative result of € 26,786.

2 ACCOUNTANT'S COMPILATION REPORT

To: the management

The financial statements of Stichting United Parent Projects 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, 2019 and the profit and loss account for the year 2019 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 Projects 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 Projects Muscular Dystrophy, Veenendaal

3 RESULTS

3.1 Comparative overview

The result for 2019 amounts to negative € 27,000 compared to € 46,000 for 2018. The results for both years can be summarized as follows:

	<u>Saldo 2019</u>	<u>Saldo 2018</u>
	€	€
Income		
Income from individuals & Legal entities	23,418	8,844
Subsidies	145,580	235,419
Gross margin	<u>168,998</u>	<u>244,263</u>
Expenses		
Expenditure on activities	179,256	182,014
Management and administration	16,572	16,649
Financial income and expenses	-44	-104
Balance	<u><u>-26,786</u></u>	<u><u>45,704</u></u>

Stichting United Parent Projects Muscular Dystrophy, Veenendaal

4 FINANCIAL POSITION

The balance sheet can be summarized as follows:

	12/31/2019		12/31/2018	
	€	€	€	€
Long term funds:				
Reserves and funds		133,014		159,800
		<u> </u>		<u> </u>
This amount is applied as follows:				
Receivables, prepayments and accrued income	6,205		100	
Cash and cash equivalents	<u>129,761</u>		<u>164,267</u>	
		135,966		164,367
Debit: Short-term debt		<u>2,952</u>		<u>4,567</u>
Working capital		<u>133,014</u>		<u>159,800</u>

Ik vertrouw erop hiermee aan uw opdracht te hebben voldaan. Tot het geven van een nadere toelichting ben ik steeds gaarne bereid.

Hoogachtend,
Stolwijk Registeraccountants & Belastingadviseurs B.V.

I.M. van Lexmond AA
Accountant-Administratieconsulent

FINANCIAL REPORT

Stichting United Parent Projects Muscular Dystrophy, Veenendaal

MANAGEMENT BOARD REPORT**General**

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

The organization in 2019

Board members

Elizabeth Vroom, chair

Ed Snitselaar, treasurer

Patricia Furlong

Sally Hofmeister

Alex Johnson

Dimitrios Athanasiou

Luca Genovese

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 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 2019 the organization had 40 member organizations from different countries and all continents. For all members see <https://www.worldduchenne.org/members/>

Activities during the year 2019

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. We organized a member meeting on February 15-17 in Rome. As the datasharing and reuse of patient data are becoming increasingly important, we produced a Duchenne FAIR Data Declaration and organized an international expert meeting on Datasharing for Duchenne in March 21-22 in Amsterdam of which the results are published.

On September 7th the yearly World Duchenne Awareness Day took place with participants from over 60 countries around the globe. The special theme for 2019 was Nutrition in DMD. This included online presentations and publications including the use and risks of nutritional supplements by Duchenne Muscular Dystrophy.

Stichting United Parent Projects Muscular Dystrophy, Veenendaal

Membership

The organization is a member of
Rare Diseases Europe - Eurordis
European Patients' Forum - EPF
Eligible member of European Medicines Agency - EMA

Members of consortia European projects (IMI included)

Share4Rare <https://www.share4rare.org/>
Vision-DMD <https://vision-dmd.info/>
Trials at Home <https://trialsathome.com/>

Income

The income of the organization is a combination of membership fees plus donations (12%) and payments in relation to the above mentioned projects (88%).

ANNUAL ACCOUNTS

Stichting United Parent Projects Muscular Dystrophy, Veenendaal

1 BALANCE SHEET AS AT DECEMBER 31, 2019
(after result appropriation)

	December 31, 2019		December 31, 2018	
	€	€	€	€
ACTIVA				
CURRENT ASSETS				
Receivables, prepayments and accrued income	(1)	6,205		100
Cash and cash equivalents	(2)	<u>129,761</u>	<u>164,267</u>	
		135,966		164,367
		<u>135,966</u>		<u>164,367</u>

		December 31, 2019		December 31, 2018	
		€	€	€	€
PASSIVA					
RESERVES AND FUNDS (3)					
Allocation reserves		187,348		-	
Unrestricted funds, general		<u>-54,334</u>		<u>159,800</u>	
			133,014		159,800
CURRENT LIABILITIES (4)					
Accounts payable		952		1,731	
Accruals and deferred income		<u>2,000</u>		<u>2,836</u>	
			2,952		4,567
			<u>135,966</u>		<u>164,367</u>

Stichting United Parent Projects Muscular Dystrophy, Veenendaal

2 STATEMENT OF THE FINANCIAL ACCOUNTS OVER 2019

	<u>Balance 2019</u>	<u>Balance 2018</u>
	€	€
Income		
Income from individuals & Legal entities	(5) 23,418	8,844
Subsidies	(6) 145,580	235,419
Sum of income	<u>168,998</u>	<u>244,263</u>
Expenses		
Expenditure on activities	(7) 179,256	182,014
Management and administration		
Other operating expenses	(8) 16,572	16,649
Balance before financial income and expense	<u>-26,830</u>	<u>45,600</u>
Financial income and expenses	(9) 44	104
Result	<u><u>-26,786</u></u>	<u><u>45,704</u></u>
Appropriation of the results		
Allocation reserves	187,348	-
Unrestricted funds, general	-214,134	45,704
	<u><u>-26,786</u></u>	<u><u>45,704</u></u>

Stichting United Parent Projects Muscular Dystrophy, Veenendaal

3 NOTES TO THE FINANCIAL STATEMENTS

3.1 GENERAL

Registered address

The registered and actual address of Stichting United Parent Projects Muscular Dystrophy (CoC file 30226334) is Landjuweel 16-8, 3905 PG, Veenendaal.

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.

Comparison with previous year

The figures for the comparative year are taken from the Draft report by Huibers Accountants en Adviseurs of November 08, 2019.

3.3 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.

Current liabilities

On initial recognition current liabilities are recognised at fair value. After initial recognition current liabilities are recognised at the amortised cost price. When there are no premiums, discounts or transaction costs, the amortised cost is equal to 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.

Stichting United Parent Projects Muscular Dystrophy, Veenendaal

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.

Stichting United Parent Projects Muscular Dystrophy, Veenendaal

3.5 NOTES TO THE BALANCE SHEET AS OF DECEMBER 31, 2019

ASSETS

1. Receivables, prepayments and accrued income

	<u>12/31/2019</u>	<u>12/31/2018</u>
	€	€
<i>Accounts receivable</i>		
Accounts receivables	6,205	100

2. Cash and cash equivalents

ABN Amro NL91ABNA0417429207	57,074	6,124
ABN Amro NL92ABNA0423265970	72,687	158,143
	<u>129,761</u>	<u>164,267</u>

The liquid resources are valued at nominal value. The liquid resources available as at December 31, 2019 are freely available to the Stichting United Parent Projects Muscular Dystrophy.

Stichting United Parent Projects Muscular Dystrophy, Veenendaal

EQUITY AND LIABILITIES
3. Equity

	12/31/2019	12/31/2018
	€	€
Allocation reserves		
Allocation reserve Share4Rare project	76,100	-
Allocation reserve Trials at Home project	111,248	-
	<u>187,348</u>	<u>-</u>
	2019	2018
	€	€
<i>Allocation reserve Share4Rare project</i>		
Stand per January 1	-	-
Result allocation	76,100	-
Carrying amount as of December 31	<u>76,100</u>	<u>-</u>
<i>Allocation reserve Trials at Home project</i>		
Stand per January 1	-	-
Result allocation	111,248	-
Carrying amount as of December 31	<u>111,248</u>	<u>-</u>
<i>Unrestricted funds, general</i>		
Carrying amount as of January 1	159,800	114,096
Allocation of financial year nett result	-214,134	45,704
Carrying amount as of December 31	<u>-54,334</u>	<u>159,800</u>

4. Current liabilities

	12/31/2019	12/31/2018
	€	€
<i>Accounts payable</i>		
Accounts payable	<u>952</u>	<u>1,731</u>
<i>Accruals and deferred income</i>		
Audit costs	2,000	-
Other costs	-	2,836
	<u>2,000</u>	<u>2,836</u>

Stichting United Parent Projects Muscular Dystrophy, Veenendaal

3.6 NOTES TO THE STATEMENT OF FINANCIAL ACTIVITIES

	Balance 2019	Balance 2018
	€	€
5. Income from individuals & Legal entities		
Membershipfee	20,759	5,227
Meetingfee	-	2,383
Donations Facebook	2,659	1,234
	<u>23,418</u>	<u>8,844</u>
6. Subsidies		
European Commission subsidy Share 4 Rare	20,850	156,375
European Commission subsidy Trials at Home	124,730	-
European government subsidy Vision DMD	-	79,044
	<u>145,580</u>	<u>235,419</u>
7. Expenditure on activities		
Expenses Share 4 Rare	51,716	49,409
Expenses Vision DMD	70,260	100,829
Expenses Trials at Home	13,483	-
Expenses WDO	28,596	17,230
Expenses WDAD	3,734	924
Expenses Meetings	11,467	13,622
	<u>179,256</u>	<u>182,014</u>
8. Other operating expenses		
Office expenses	1,630	1,485
Publicity expenses	1,184	1,415
General expenses	13,758	13,749
	<u>16,572</u>	<u>16,649</u>
<i>Office expenses</i>		
Automation costs	101	90
Telephone and internet costs	1,029	1,195
Contributions and subscriptions	500	200
	<u>1,630</u>	<u>1,485</u>
<i>Publicity expenses</i>		
Gifts	55	158
Website costs	1,129	1,257
	<u>1,184</u>	<u>1,415</u>
<i>General expenses</i>		
Audit costs	12,548	12,657
Liability insurance	962	962
Banking costs	248	130
	<u>13,758</u>	<u>13,749</u>

Stichting United Parent Projects Muscular Dystrophy, Veenendaal

	<u>Balance 2019</u>	<u>Balance 2018</u>
	€	€
9. Financial income and expenses		
Interest and similar income	44	104
<i>Interest and similar income</i>		

Stichting United Parent Projects Muscular Dystrophy, Veenendaal

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.