

Stichting Duchenne Data Foundation  
Warmoesdreef 10  
4614 HC BERGEN OP ZOOM

**Ref:** 36278/11201/IVL/hdb

**De Meern**, 19 juni 2020

Betreft: Jaarrekening 2019.

Beste Mirjam,

Hierbij ontvang je de jaarrekening 2019 van Stichting Duchenne Data Foundation.

In verband met de privacy-wetgeving sturen wij dit overzicht via PKI signing en verzoeken je hieronder te tekenen voor ontvangst, zodat wij dit in ons dossier kunnen opslaan.

Met vriendelijke groet,

drs. I.M. van Lexmond AA

Voor ontvangst:

Stichting Duchenne Data Foundation, namens  
Mirjam Franken

**STICHTING DUCHENNE DATA FOUNDATION  
AT BERGEN OP ZOOM**

Annual Report 2019

June 19, 2020

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## **AUDITOR'S REPORT**

To the management of  
Stichting Duchenne Data Foundation  
Warmoesdreef 10  
4614 HC Bergen op Zoom

<i>Reference</i>	<i>Processed by</i>	<i>Date</i>
11201	HB-IL	June 19, 2020

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 € 422,030 and the statement of financial activities with a result of € 142,506.

## **2 ACCOUNTANT'S COMPILATION REPORT**

To: the management

The financial statements of Stichting Duchenne Data Foundation at Bergen op Zoom 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 Duchenne Data Foundation. 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 Duchenne Data Foundation, Bergen op Zoom**
**3 RESULTS**
**3.1 Development of income and expenses**

The results for 2019 amounts € 142,506 to € 59,319 for 2018. The results for both years can be summarized as follows:

	2019	2018
	€	€
<b>Income</b>		
Income from individuals	-	6,608
Other income	359,120	158,855
<b>Gross margin</b>	359,120	165,463
	359,120	165,463
<b>Expenditure</b>		
Expenditure on activities	204,330	96,751
Office expenses	2,259	659
Publicity expenses	609	-
General expenses	9,416	8,734
<b>Sum of expenses</b>	216,614	106,144
<b>Result</b>	142,506	59,319

**Stichting Duchenne Data Foundation, Bergen op Zoom**
**4 FINANCIAL POSITION**

The balance sheet can be summarized as follows:

	12/31/2019		12/31/2018	
	€	€	€	€
<b>Long term funds:</b>				
Reserves and funds		358,486		215,981
		<u>          </u>		<u>          </u>
This amount is applied as follows:				
Receivables, prepayments and accrued income	69,000		63,959	
Cash and cash equivalents	<u>353,030</u>		<u>168,587</u>	
		422,030		232,546
Debit: Short-term debt		63,544		16,565
		<u>          </u>		<u>          </u>
Working capital		<u>358,486</u>		<u>215,981</u>

Yours sincerely,  
 Stolwijk Registeraccountants & Belastingadviseurs B.V.

I.M. van Lexmond AA

## **FINANCIAL REPORT**



**Stichting Duchenne Data Foundation, Bergen op Zoom**

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**MANAGEMENT BOARD REPORT***General*

On January, 15 2019 the name of the Stichting UPPMD Data Foundation was officially changed into Stichting Duchenne Data Foundation.  
Stichting Duchenne Data Foundation (CoC file 64601188) has it's registered office in Bergen op Zoom.

*Composition of the Board*

The board members are:  
Paliouras, G. (chairman)  
Franken - Verbeek, M.J.F. (secretary)  
Fischer, R.K. (member) from 16-04-2020

*Goal, strategy and activities*

With a global reach the Stichting Duchenne Data Foundation is a spinoff of World Duchenne Organization, the global patient organization. Stichting Duchenne Data Foundation has as its purpose:

1. Worldwide collaboration between Duchenne Parent organisations in order to enhance the understanding of

- the course of DMD/BMD,
- the effects of treatments,
- the needs and preferences of DMD/BMD patients,
- all other aspects relevant to the lives of DMD/BMD patients.

2. The Duchenne Data Foundation will in particular devote itself to the realisation of this task by way of the following goals:

- Collect data from PROs, PROMs, PMR etc. in a data collection hub.
- Integrate worldwide sources of information for DMD such as databanks, biobanks and registries in one unified environment.
- Provide solid and safe information to parents, clinicians, regulators and other stakeholders.
- Promote and support research.
- Develop tools for better use of existing data.

**ANNUAL ACCOUNTS 2019**

**Stichting Duchenne Data Foundation, Bergen op Zoom**

**1 BALANCE SHEET AS AT DECEMBER 31, 2019**

(after result appropriation)

	December 31, 2019		December 31, 2018	
	€	€	€	€
<b>ACTIVA</b>				
<b>CURRENT ASSETS</b>				
<b>Receivables, prepayments and accrued income</b>	(1)			
Account receivable		69,000		63,959
<b>Cash and cash equivalents</b>	(2)	353,030		168,587
		422,030		232,546

	December 31, 2019		December 31, 2018	
	€	€	€	€
<b>PASSIVA</b>				
<b>RESERVES AND FUNDS</b> (3)				
Unrestricted funds, designated	250,000		-	
Unrestricted funds, general	<u>108,486</u>		<u>215,981</u>	
		358,486		215,981
<b>CURRENT LIABILITIES</b> (4)				
Account payable	32,354		15,315	
Accruals and deferred income	<u>31,190</u>		<u>1,250</u>	
		63,544		16,565
		<u>422,030</u>		<u>232,546</u>

**Stichting Duchenne Data Foundation, Bergen op Zoom**
**2 STATEMENT OF THE FINANCIAL ACTIVITIES OVER 2019**

	<u>Balance 2019</u>	<u>Balance 2018</u>
	€	€
<b>Income</b>		
Income from individuals	(5) -	6,608
Sum of income	-	6,608
Other income	(6) 359,120	158,855
<b>Sum of income</b>	359,120	165,463
<b>Expenses</b>		
<b>Expenditure on activities</b>	204,330	96,751
<b>Costs of support</b>		
Office expenses	(8) 2,259	659
Publicity expenses	(9) 609	-
General expenses	(10) 9,416	8,734
	12,284	9,393
<b>Result</b>	<u>142,506</u>	<u>59,319</u>
<b>Appropriation of the results</b>		
Unrestricted funds, designated	250,000	-
Unrestricted funds, general	-107,494	59,319
	<u>142,506</u>	<u>59,319</u>

**Stichting Duchenne Data Foundation, Bergen op Zoom**

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**3 NOTES TO THE FINANCIAL STATEMENTS****GENERAL****Activities**

The activities of Stichting Duchenne Data Foundation (CoC file 64601188), with registered offices in Bergen op Zoom, mainly consist of the following: The worldwide collaboration between Duchenne Parent Organizations in order to improve the understanding of the course of disease process, the effect of treatment methods, the needs and preferences and all other aspects of all those affected by Duchenne muscular dystrophy (DMD and BMD).

**Registered address**

The registered and actual address of Stichting Duchenne Data Foundation (CoC file 64601188) is Warmoesdreef 10, 4614 HC in Bergen op Zoom.

**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 motive (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 report by Huibers Accountants and Adviseurs of January, 22 2020 with which a composition statement has been issued.

**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.

## **ACCOUNTING PRINCIPLES FOR THE DETERMINATION OF THE RESULT**

### **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.

**4 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>Account receivable</i>		
Account receivable	<u>69,000</u>	<u>63,959</u>

**2. Cash and cash equivalents**

NL75ABNA0620549920	353,030	167,620
Money in transit	-	967
	<u>353,030</u>	<u>168,587</u>

The liquid resources are valued at nominal value. The liquid resources available as at December 31, 2019 are freely available to the Stichting Duchenne Data Foundation.



## Stichting Duchenne Data Foundation, Bergen op Zoom

**EQUITY AND LIABILITIES**

	<u>12/31/2019</u>	<u>12/31/2018</u>
	€	€
<b>3. Reserves and funds</b>		
Unrestricted funds, designated	250,000	-
Unrestricted funds, general	108,486	215,981
	<u>358,486</u>	<u>215,981</u>
<b>Unrestricted funds, designated</b>		
Selfinitiated Projects	100,000	-
Continuity reserves	150,000	-
	<u>250,000</u>	<u>-</u>
	<u>2019</u>	<u>2018</u>
	€	€
<i>Selfinitiated Projects</i>		
Stand per January 1	-	-
Result allocation	100,000	-
Carrying amount as of December 31	<u>100,000</u>	<u>-</u>
<i>Continuity reserves</i>		
Stand per January 1	-	-
Result allocation	150,000	-
Carrying amount as of December 31	<u>150,000</u>	<u>-</u>
<i>Unrestricted funds, general</i>		
Carrying amount as of January 1	215,980	156,662
Allocation of financial year nett result	-107,494	59,319
Carrying amount as of December 31	<u>108,486</u>	<u>215,981</u>
<b>4. Current liabilities</b>		
	<u>12/31/2019</u>	<u>12/31/2018</u>
	€	€
<i>Account payable</i>		
Account payable	<u>32,354</u>	<u>15,315</u>

**Stichting Duchenne Data Foundation, Bergen op Zoom**

	<u>12/31/2019</u>	<u>12/31/2018</u>
	€	€
<i>Other liabilities and Accruals and deferred income</i>		
Audit costs	1,750	1,250
Cost of Patient Academy	<u>29,440</u>	<u>-</u>
	<u><u>31,190</u></u>	<u><u>1,250</u></u>

**Stichting Duchenne Data Foundation, Bergen op Zoom**
**5 NOTES TO THE STATEMENT OF FINANCIAL ACTIVITIES 2019**

	Balance 2019	Balance 2018
	€	€
<b>5. Income from individuals</b>		
Donations	-	6,608
<b>6. Other income</b>		
Income Community Advisory Board	156,250	-
Income Patient Academy	112,370	-
Income Breath Your Story	20,000	-
Income Projects	70,500	-
Income unspecified	-	158,855
	<u>359,120</u>	<u>158,855</u>
<b>7. Expenditure on activities</b>		
Costs of congress and seminars	4,756	318
Costs of Community Advisory Board	66,597	-
Costs of MAP	4,193	-
Costs of Data Share Meeting	15,645	-
Costs of WMS	946	-
Costs of Patient Academy	71,859	-
Cost of Psycho Project	2,700	-
Costs of Meeting Rome	6,094	-
Cost of Centro Clinico Nemo	23,000	-
Cost of Arimvideo	8,540	-
Cost of projects unspecified	-	96,433
	<u>204,330</u>	<u>96,751</u>
<b>Emoluments of directors and supervisory directors</b>		
<b>Staff</b>		
During 2019, no employees were employed on a full-time basis.(2018: 0)		
<b>Other operating expenses</b>		
<b>8. Office expenses</b>		
Office supplies	18	-
Automation costs	2,241	659
	<u>2,259</u>	<u>659</u>
<b>9. Publicity expenses</b>		
Publicity and advertisement	576	-
Gifts	33	-
	<u>609</u>	<u>-</u>

**Stichting Duchenne Data Foundation, Bergen op Zoom**

	<u>Balance 2019</u>	<u>Balance 2018</u>
	€	€
<b>10. General expenses</b>		
Audit costs	8,211	8,182
Bank costs	649	552
Exchange rate differences	416	-
Other general expenses	140	-
	<u>9,416</u>	<u>8,734</u>

## **OTHER INFORMATION**

**Stichting Duchenne Data Foundation, Bergen op Zoom**

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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.