

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

Annual Report 2020

October 5, 2021

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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	October 5, 2021

Dear members of the Executive Board,

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

## **1 ENGAGEMENT**

In accordance with your instructions we have compiled the annual account 2020 of your company, including the balance sheet with counts of € 444,255 and the statement of financial activities with a result of € 80,661.

## **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, 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 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**


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**3 RESULTS**
**3.1 Development of income and expenses**

The results for 2020 amounts € 80,661 to € 142,506 for 2019. The results for both years can be summarized as follows:

	2020	2019
	€	€
<b>Income</b>		
Subsidies	66,549	-
Other income	177,400	359,120
<b>Gross margin</b>	<u>243,949</u>	<u>359,120</u>
<b>Expenditure</b>		
Expenditure on activities	143,753	204,330
Office expenses	3,677	2,259
Publicity expenses	296	609
General expenses	15,562	9,416
<b>Sum of expenses</b>	<u>163,288</u>	<u>216,614</u>
<b>Result</b>	<u><u>80,661</u></u>	<u><u>142,506</u></u>

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

**4 FINANCIAL POSITION**

The balance sheet can be summarized as follows:

	12/31/2020		12/31/2019	
	€	€	€	€
<b>Long term funds:</b>				
Reserves and funds		439,146		358,486
		<u>439,146</u>		<u>358,486</u>
This amount is applied as follows:				
Receivables, prepayments and accrued income	78,862		69,000	
Cash and cash equivalents	<u>365,393</u>		<u>353,030</u>	
		444,255		422,030
Debit: Short-term debt		5,109		63,544
Working capital		<u>439,146</u>		<u>358,486</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 its 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 2020**

**Stichting Duchenne Data Foundation, Bergen op Zoom**
**1 BALANCE SHEET AS AT DECEMBER 31, 2020**

(after result appropriation)

	December 31, 2020		December 31, 2019	
	€	€	€	€
<b>ACTIVA</b>				
<b>CURRENT ASSETS</b>				
<b>Receivables, prepayments and accrued income</b>	(1)			
Account receivable		77,900		69,000
Other receivables, deferred assets		962		-
		<u>78,862</u>		<u>69,000</u>
<b>Cash and cash equivalents</b>	(2)			
		365,393		353,030
		<u>444,255</u>		<u>422,030</u>

	December 31, 2020		December 31, 2019	
	€	€	€	€
<b>PASSIVA</b>				
<b>RESERVES AND FUNDS</b>	(3)			
Unrestricted funds, designated	250,000		250,000	
Designated reserve projects - BIND	48,820		-	
Unrestricted funds, general	<u>140,326</u>		<u>108,486</u>	
		439,146		358,486
<b>CURRENT LIABILITIES</b>	(4)			
Account payable	5,000		32,354	
Accruals and deferred income	<u>109</u>		<u>31,190</u>	
		5,109		63,544
		<u>444,255</u>		<u>422,030</u>

**Stichting Duchenne Data Foundation, Bergen op Zoom**
**2 STATEMENT OF THE FINANCIAL ACTIVITIES OVER 2020**

	<u>Balance 2020</u>	<u>Balance 2019</u>
	€	€
<b>Income</b>		
Subsidies	(5) 66,549	-
Other income	(6) 177,400	359,120
<b>Sum of income</b>	243,949	359,120
<b>Expenses</b>		
<b>Expenditure on activities</b>	143,753	204,330
<b>Costs of support</b>		
Office expenses	(9) 3,677	2,259
Publicity expenses	(10) 296	609
General expenses	(11) 15,562	9,416
	<u>19,535</u>	<u>12,284</u>
<b>Result</b>	<u>80,661</u>	<u>142,506</u>
<b>Appropriation of the results</b>		
Unrestricted funds, designated	-	250,000
Designated reserve projects - BIND	48,820	-
Unrestricted funds, general	31,841	-107,494
	<u>80,661</u>	<u>142,506</u>

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

The registered and actual address of Stichting Duchenne Data Foundation is Warmoesdreef 10, 4614 HC, P.O. Box 0000, 0000 XX in Bergen op Zoom of business and is registered at the chamber of commerce under number 64601188.

##### **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.

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**

###### **Securities**

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****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.

**Gross margin**

The gross operating profit and loss comprises net turnover, the changes in inventories of finished goods and work in progress, work performed by the entity and capitalised, other operating income, cost price and cost of outsourced work and other external charges.

**Government subsidies**

Operating subsidies are recorded as income in the profit and loss account in the year in which the subsidised costs were incurred or income was lost or when there was a subsidised operating deficit. Income is recognised when it is probable that it will be received.

Subsidies related to investments in tangible fixed assets are deducted from the asset to which they relate and recorded in the profit and loss account as part of the amortisation costs.

**Expenses general**

Costs are determined on a historical basis and are attributed to the reporting year to which they relate.

**Employee expenses**

The benefits payable to personnel are recorded in the profit and loss account on the basis of the employment conditions.

**Amortisation and depreciation**

**4 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>Account receivable</i>		
Account receivable	<u>77,900</u>	<u>69,000</u>
<i>Other receivables and prepayments</i>		
Insurance	<u>962</u>	<u>-</u>
<b>2. Cash and cash equivalents</b>		
NL75ABNA0620549920	<u>365,393</u>	<u>353,030</u>

The liquid resources are valued at nominal value. The liquid resources available as at December 31, 2020 are freely available to the Stichting Duchenne Data Foundation.

## Stichting Duchenne Data Foundation, Bergen op Zoom

**EQUITY AND LIABILITIES**

	12/31/2020	12/31/2019
	€	€
<b>3. Reserves and funds</b>		
Unrestricted funds, designated	250,000	250,000
Designated reserve projects - BIND	48,820	-
Unrestricted funds, general	140,326	108,486
	<u>439,146</u>	<u>358,486</u>
<b>Unrestricted funds, designated</b>		
Selfinitiated Projects	100,000	100,000
Continuity reserves	150,000	150,000
	<u>250,000</u>	<u>250,000</u>
	<u>2020</u>	<u>2019</u>
	€	€
<i>Selfinitiated Projects</i>		
Carrying amount as of January 1	100,000	-
Result allocation	-	100,000
Carrying amount as of December 31	<u>100,000</u>	<u>100,000</u>
<i>Continuity reserves</i>		
Carrying amount as of January 1	150,000	-
Result allocation	-	150,000
Carrying amount as of December 31	<u>150,000</u>	<u>150,000</u>
<i>Designated reserve projects - BIND</i>		
Carrying amount as of January 1	-	-
Result allocation	48,820	-
Carrying amount as of December 31	<u>48,820</u>	<u>-</u>
<i>Unrestricted funds, general</i>		
Carrying amount as of January 1	108,485	215,980
Allocation of financial year nett result	31,841	-107,494
Carrying amount as of December 31	<u>140,326</u>	<u>108,486</u>



Stichting Duchenne Data Foundation, Bergen op Zoom

**4. Current liabilities**

	<u>12/31/2020</u>	<u>12/31/2019</u>
	€	€
<i>Account payable</i>		
Account payable	5,000	32,354
	<u>5,000</u>	<u>32,354</u>
<i>Other liabilities and Accruals and deferred income</i>		
Audit costs	-	1,750
Nett income	109	-
Cost of Patient Academy	-	29,440
	<u>109</u>	<u>31,190</u>

## Stichting Duchenne Data Foundation, Bergen op Zoom

## 5 NOTES TO THE STATEMENT OF FINANCIAL ACTIVITIES 2020

	Balance 2020	Balance 2019
	€	€
<b>5. Subsidies</b>		
European Commission subsidy BIND	66,549	-
<b>6. Other income</b>		
Income Community Advisory Board	61,400	156,250
Income Patient Academy	16,000	112,370
Income Breath Your Story	-	20,000
Income Projects	-	70,500
Income Digital D&B Program	100,000	-
	<u>177,400</u>	<u>359,120</u>
<b>7. Expenditure on activities</b>		
Costs of congress and seminars	1,945	4,756
Costs of Community Advisory Board	29,382	66,597
Costs of MAP	25,277	4,193
Costs of Data Share Meeting	-	15,645
Costs of WMS	-	946
Costs of Patient Academy	17,158	71,859
Cost of Psycho Project	15,591	2,700
Costs of Meeting Rome	271	6,094
Cost of Centro Clinico Nemo	-	23,000
Cost of Arimvideo	-	8,540
Costs of EURO NMD	2,890	-
Costs of Digital D&B Program	10,000	-
Costs of DDF Repository	23,510	-
Cost of BIND	17,729	-
	<u>143,753</u>	<u>204,330</u>
<b>8. Employee expenses</b>		
Wages and salaries	12,943	-
Social security charges	2,995	-
Other personnel costs	-15,938	-
	<u>-</u>	<u>-</u>
<i>Wages and salaries</i>		
Gross wages	11,984	-
Bruto vakantiegeld	959	-
	<u>12,943</u>	<u>-</u>
<i>Social security charges</i>		
Other social charges	2,995	-
	<u>2,995</u>	<u>-</u>

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

	Balance 2020	Balance 2019
	€	€
<i>Other personnel costs</i>		
Travelling expenses	894	-
Allocated labour costs Patient Academy	-16,832	-
	<u>-15,938</u>	<u>-</u>
<b>Emoluments of directors and supervisory directors</b>		
<b>Staff</b>		
During 2020 1 employee was employed on a full-time basis.(2019: 0)		
<b>Other operating expenses</b>		
<b>9. Office expenses</b>		
Office supplies	87	18
Automation costs	3,590	2,241
	<u>3,677</u>	<u>2,259</u>
<b>10. Publicity expenses</b>		
Publicity and advertisement	296	576
Gifts	-	33
	<u>296</u>	<u>609</u>
<b>11. General expenses</b>		
Audit costs	7,404	8,211
Auditcosts previous years	3,824	-
consultancy fees	1,577	-
Insurance costs	977	-
Bank costs	1,806	649
Exchange rate differences	-	416
Other general expenses	-26	140
	<u>15,562</u>	<u>9,416</u>

## **OTHER INFORMATION**

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

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**OTHER INFORMATION**

**1 Audit**

your company has utilized the exemption from an audit by virtue of art. 2:396, paragraph 7 of the Dutch Civil Code.