Financial accounts - December 31, 2020

European Neuro Muscular Centre

(a foundation under Dutch Law)

Lt. Gen. van Heutszlaan 6 3743 JN Baarn

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Activity report

The annual impact report is available at the office of the foundation.

A PDF version of this report can be downloaded from the ENMC website (www.enmc.org).

Balance sheet as at December 31, 2020

After proposal profit appropriation

ASSETS		<u>31-12-2020</u> €	31-12-2019 €
Current assets Other receivables	1	4.990	27.029
Cash at banks	2	<u>573.745</u> 578.735	<u>477.725</u> 504.754
EQUITY AND LIABILITIES		376.733	304.734
Equity	3	356.625	312.558
Provisions Workshop provisions	4	185.622	155.762
Current liabilities Other payables	5	36.488	36.434
		578.735	504.754

Statement of income and expenses for the year 2020

		Budget	
	2020	2020	2019
	€	€	€
Income		12	
Member contributions	231.000	231.000	210.000
Associated member contributions	10.000	<i>15.000</i>	10.000
Company Forum contributions	75.791	90.00 0	91.151
Other contributions	1.000	10.000	22.165
Total income	317.791	346.000	333.316
			, ,
Expenses			
Personnel expenses	156.237	146.000	144.090
Housing expenses	11.326	11.500	11.421
Activity expenses	68.059	140.000	115.233
Organizational expenses	37.996	47.300	44.365
Total operating expenses	273.618	344.800	315.109
Operating result	44.173	1.200	18.207
Interest income			117
Net result	44.067	1.200	18.324
A seed a deather of month			
Appropriation of result			
Continuity reserve	<u></u>	-	-3.131
Reserve for 25th anniversary - withdrawal	-	-	-3.131 -4.012
Reserve for 25th anniversary - release	-		-4.012 -29.845
Reserve for additional workshop costs - withdrawal	80.000	-	-29.845
Development reserve		-	-
Development reserve - withdrawal	-3.652	1 200	-
Other free reserves	32.281_	1.200	55.312_
	44.067	1.200	18.324

Cashflow statement for the year 2020

		2020		2019
	€	€	€	€
Operating result		44.173		18.207
Adjustment for:				
Movement in provisions		29.860		-2 0.450
Changes in working capital:				
Other accounts receivable	22.039		-15.169	
Current liabilities	54_		-12.116	
	_	22.093	(9	-27.285
Cash flow from operating activities		96.126		-29.528
Interest received	-	-106		117
Cash movement	_	96.020		-29.411
	_		19	
Balance as at beginning of the financial year		477.725		507.136
Movement during the financial year	_	96.020	19	-29.411
Balance at the end to the financial year	_	573.745		477.725

Notes to the financial accounts

Registered address and registration number trade register

The registered and actual address of The European Neuro Muscular Centre is Lt. Gen. Van Heutszlaan 6, 3743 JN in Baarn. The foundation is registered at the trade register under number 41190058.

General

This report was prepared in accordance with Guideline C1 for the reporting of Small sized non-profit organizations as published by the Dutch Accounting Standards Board (Raad voor de Jaarverslaggeving).

The financial accounts are drawn up in Euros.

Activities

The European Neuro Muscular Centre (ENMC) in Baarn was founded on 24 November, 1992 under Dutch Law. The objective of the foundation is to promote research in the field of diagnosis and treatment of neuromuscular diseases and to collect and distribute useful and reliable information about these diseases. To meet this objective, the foundation mainly organizes workshops which are its core business. The workshops are held in the Netherlands.

The foundation is financed and steered by a number of National Patient Associations for neuromuscular diseases in Europe. In addition, it receives co-support from other neuromuscular organizations and from multiple companies developing treatments and diagnostic tools for patients with neuromuscular conditions.

The foundation has its statutory seat in Baarn and holds its office in the building of Spierziekten Nederland.

Accounting policies in respect of the valuation of assets and liabilities

General

Assets and liabilities are accounted at historical costs and unless stated otherwise are shown at their nominal value.

Accounts receivable

The accounts receivable are valued at amortised cost price which generally equals the nominal value. Provisions deemed necessary for possible bad losses are deducted. These provisions are determined by individual assessment of receivables.

Provisions

Unless stated otherwise the other provisions are valued at the face value of the expenditures that are expected to be necessary for settling the related obligations.

Current liabilities

The current liabilities are valued at amortised cost price which generally equals the nominal value.

Accounting policies in respect of result determination

General

The result represents the difference between the contributions received and the expenses and other charges for the year. The results on transactions are recognized in the year in which they are realized and/or approved. The approved transactions concern the estimated expenses of workshops approved in this year and of the committed contributions of new co-sponsors.

Other operating expenses

Expenses are taken into account under the historical cost convention and allocated to the period concerned.

Activity expenses

Expenses are taken into account at the historical cost. Provisions (best estimate of the expected costs) are made for workshops that are approved but not yet completed at the end of the year. The workshops expenses consist of actually paid expenses as well as of approved costs for workshops.

Principles of the cash flow summary

The cash flow statement is prepared according to the indirect method.

The funds in the cash flow statement consist of cash.

Interest received is entered under the cash flow from operating activities.

Notes to the balance sheet

Current assets

1 Other receivables		
	31-12-2020	31-12-2019
	€	€
Other receivables and accrued assets		
Contributions	4.124	25.000
Prepaid expenses	866	1.912
Bank interest		117
	4.990	27.029
2 Cash at banks		
ING Top rente 68.44.14.880	196.995	100.986
ING RC 68.44.14.880	376.750	376.739
	573.745	477.725
3 Equity		
Continuity reserve	200.000	200.000
Reserve for 25th anniversary	-	-
Reserve for additional workshop costs		-
Development reserve	76.348	-
Other (free) reserves	80.277	112.558
	255 535	242.550
	356.625	312.558
A minimum of € 25.000 will remain in Other free reserves to be able to cover	unexpected cost	S.
	2020	2010
	2020	2019
	€	€
Continuity reserve	200.000	200.000
Balance as at January 1	200.000	200.000
Appropriation of result		:
D. L	200.000	200.000
Balance as at December 31		200.000

The continuity reserve is established to be able to execute approved workshops, in case of a shortfall in raising the necessary funds. The level is set on € 200.000 by the Executive Committee (April 14, 2016), which is the amount necessary to keep the office running and perform the approved workshops for one year.

	20 20	2019
	€	€
Developmental reserve (special-purpose reserve)		
Balance as at January 1	-	-
Appropriation of result	80.000	
Appropriation of result: Expenses paid in the bookyear	-3.652	
	76.348	-

The Developmental reserve (€80.000) is a special purpose reserve and is meant for financial resources for the implementation of the ENMC Mentoring Programme and the further development of ENMC workshops for the period 2021-2024. It covers also extra office resources and financial resources e.g. to create awareness in the neuromuscular field and to set-up online workshops. In addition, investments may need to be done to set-up online workshops.

The Executive Committee has approved the Developmental reserve on 10 November 2020.

	2020	2019
	€	€
Other free reserves		
Balance as at January 1	112.558	57.246
Appropriation of result	-32.281	55.312
Balance as at December 31	80.277	112.558

The operational result of € 44.067 is added to the Other free reserves (01-01-2020: € 112.558), from which € 80.000 was deducted for the Developmental reserve. Since an amount of € 3.652 was used in 2020 of this Developmental reserve, this amount can also be added to the Other free reserves, resulting in a balance of € 80.277. The total appropriation of result therefore is -€ 32.281.

	31-12-2020 €	<u>31-12-2019</u> €
4 Workshop provisions		
Workshop 246	-	3.621
Workshop 247	-	4.373
Workshop 248	1.000	1.416
Workshop 249	1.995	13.398
Workshop 250	849	1.287
Workshop 251	3.000	11.667
Workshop 252	3.778	15.000
Workshop 253	15.000	15.000
Workshop 254	15.000	15.000
Workshop 255	15.000	15.000
Workshop 256	15.0 00	15.000
Workshop 257	1 5.0 00	15.000
Workshop 258	1 5.0 00	15.000
Workshop 259	15.000	15.000
Workshop 260	14.000	-
Workshop 261	14.000	-
Workshop 262	14.000	-
Workshop 263	14.000	-
Workshop 264	14.000	<u> </u>

	185.622	155.762

Based on the average actual costs of the last 10 workshops held at the Courtyard Marriott hotel (€ 13.552), a new workshop provision number was proposed at the Executive Committee meeting of 14 November 2019: It was decided to install a provisional amount of € 14.000 per workshop as of 1 January 2020.

	2020	2019
Workshop 246 (administratively closed)	C	Č
Balance as at January 1	3.621	15.000
Provision		
Expenses paid in the bookyear		-11.379
Not declared	-3.621	-
Balance as at December 31	<u>-</u>	3.621
Workshop 247 (administratively closed)		
Balance as at January 1	4.373	15.000
Provision		
Expenses paid in the bookyear	-355	-10.627
Not declared	-4.018	
Balance as at December 31		4.373
Workshop 248		
Balance as at January 1	1.416	15.000
Provision	290	
Expenses paid in the bookyear	-706	-13.584
Balance as at December 31	1.000	1.416

	2020	2019
Workshop 249		
Balance as at January 1	13.398	15.000
Provision		
Expenses paid in the bookyear	11.403	-1.602
Balance as at December 31	1.995	13.398
Workshop 250		
Balance as at January 1	1.287	15.000
Provision		
Expenses paid in the bookyear	-438	-13.713
Balance as at December 31	849	1.287
Workshop 251		
Balance as at January 1	11.667	_
Provision	962	15.000
Expenses paid in the bookyear	-9.629	-3.333

Balance as at December 31	3.000	11.667
Workshop 252		
Balance as at January 1	15.000	-
Provision		15.000
Expenses paid in the bookyear	-11.222	
Balance as at December 31	3.778	15.000
Workshop 253		
Balance as at January 1	15.000	_
Provision		15.000
Expenses paid in the bookyear	<u> </u>	,
Balance as at December 31	15.000	15.000
Workshop 254		
Balance as at January 1	15.000	-
Provision		15.000
Expenses paid in the bookyear		
Balance as at December 31	15.000	15.000
balance as at December 51		
Workshop 255		
Balance as at January 1	15.000	-
Provision		15.000
Expenses paid in the bookyear	-	S
Balance as at December 31	15.000	15.000

	2020	2019
Workshop 256		
Balance as at January 1	15.000	-
Provision		15.000
Expenses paid in the bookyear		
Balance as at December 31	15.000	15.000
Workshop 257		
Balance as at January 1	15.000	-
Provision		15.000
Expenses paid in the bookyear		-
Balance as at December 31	15.000	15.000
Workshop 258		
Balance as at January 1	15.000	_
Provision	23.000	15.000
Expenses paid in the bookyear		<u>-</u>
Balance as at December 31	15.000	15.000
Workshop 259		
Balance as at January 1	15.000	-
Provision		15.000
Expenses paid in the bookyear		-
Balance as at December 31	15.000	15.000
Workshop 260		
Balance as at January 1		_
Provision	14.000	-
Expenses paid in the bookyear		
	44.000	
Balance as at December 31	14.000	
Workshop 261		
Balance as at January 1	-	_
Provision	14.000	-
Expenses paid in the bookyear		
Balance as at December 31	14.000	-
Workshop 262		
Balance as at January 1	-	_
Provision	14.000	-
Expenses paid in the bookyear		
	4.6	
Balance as at December 31	14.000	

Workshop 263	2020	€
Balance as at January 1	_	_
Provision	14.000	_
Expenses paid in the bookyear	-	-
Balance as at December 31	14.000	
Workshop 264		
Balance as at January 1	-	-
Provision	14.000	-
Expenses paid in the bookyear		
Balance as at December 31	14.000	-
Current liabilities		
	31-12-2020	31-12-2019
	€	€
5 Other payables		
Payable for glossy	-	2.000
Rental and service charges SN	11.574	11.300
Creditors	1.790	3.021
Accounting and audit fees	6.713	6.714
Wage tax	9.624	8.379
Pension premium	2.000	1.074
Accrued holiday allowance	4.787	3.946
Payables to organisers of workshop administratively closed		
	36.488	36.434

Subsequent events

Regarding the Corona crisis, we have some doubt about the continuity of the organization, but not to the extent that there is reasonable doubt. It is expected that the organization will not have to use the government-provided facilities since ENMC has a continuity reserve which is available in cash in case of short-fall of income due to Corona or other emergencies. Furthermore, the number of approved workshop applications were twice as low as budgeted for in 2020. Therefore, ENMC will have extra Other free reserves available to manage any unexpected expenditures in the following year.

Notes to the statements of activities

	2020	Budget 2020	2019
	€	€	€
6 Member contributions			
Deutsche Gesellschaft für Muskelkranke (Germany)	33.000	-	30.000
Muscular Dystrophy UK (United Kingdom)	33.000	-	30.000
Muskelsvindfonden (Denmark)	33.000	-	30.000
Fondazione Telethon (Italy)	33.000	-	30.000
Association Française contre les Myopathies (France)	33.000	-	30.000
Schweizerische Stiftung für die Erforschung der	33.000		
Muskelkrankheiten (Switzerland)		-	30.000
Prinses Beatrix Spierfonds (The Netherlands)	16.500	-	15.000
Spierziekten Nederland (The Netherlands)	16.500	-	15.000
Total budget member contributions		231.000	-
	231.000	231.000	210.000
7 Associated member contributions			
Finnish Neuromuscular Association (Finland)	5.000		5.000
Österreichische Muskelforschung (Austria)	5.000		5.000
Total budget associated member contributions		15.000	
	10.000	15.000	10.000
8 Company Forum contributions			
Sanofi Genzyme	20.000	_	20,000
Roche	20.000		20.000
Lupin Neuroscienses	10.000	· _	-
Santhera Pharmaceuticals	20.000	_	5.000
CSL Behring		-	20.000
Amicus Therapeutics	5.000	_	5.000
Ionis Pharmaceuticals	4.124	_	4.484
Biogen	6.667		6.667
Novartis (AveXis)	5.000		5.000
WallacOy/PerkinElmer	5.000		5.000
Total budget Company Forum		90.000	
	<u>75.791</u>	90.000	91.151

9 Other contributions	2020	Budget €	2019 €
SMA Europe (workshop 244)		_	5.000
MDA USA (workshop 244)		-	4.364
MAP Nemaline MD-UK project (workshop 250)		-	700
A Foundation Building Strength (AFBS) (workshop 250)		-	5.400
Valerion Therapeutics (workshop 251)		-	4.480
Maze Therapeutics (workshop 251)		-	2.221
Philips (workshop 252)	1.000	_	-
Total budget other contributions	·	10.000	F
	1.000	10.000	22.165

In 2020, 23% of the total income was received from companies and 77% from non-companies (neuromuscular patient organisations and fundraising organisations). The ENMC aims to cap the level of income from companies to 30% of the total income.

10 Personnel expenses

Salaries	105.894	_	98.848
Social charges	19.327	_	19.941
Pensions	20.580	_	13.016
Movement to accrual holiday allowance	7.775	_	7.154
Insurance sickleave current year	1.680	-	3.730
Other personnel expenses	981	_	1.401
Total budget salaries (including workshop assistents)	-	146.000	_

	156.237	146.000	144.090

Average numbers of employees

During the year 2020 ENMC employed, converted to full-time equivalents, on average 1,5 employees (2019: average 1,5).

11 Housing expenses

Office rental and services	11.326	11.500	11.421
Office rental and services	11.520	11.500	11.421

	2020	Budget 2020	2019
	€	€	€
12 Activity expenses			
Workshop 235	-		3.131
Workshop 248	290		-
Workshop 249	-		-
Workshop 250	-		-
Workshop 251	962		15.000
Workshop 252	-		15.000
Workshop 253	-		15.000
Workshop 254	-		15.000
Workshop 255	-		15.000
Workshop 256	-		15.000
Workshop 257	-		15.000
Workshop 258	-		15.000
Workshop 259	-		15.000
Workshop 260	14.000		-
Workshop 261	14.000		-
Workshop 262	14.000		-
Workshop 263	14.000		-
Workshop 264	14.000		-
Developmental projects	3.652		=
Additional amounts previous workshops	794	-	264
Non-declared amounts previous years	-7.639	-	-23.162
Total budget activity expenses		140.000_	
	68.059	140.000	115.233

In 2020, ENMC made a budget provision for ten (10) workshops to be approved in the two review rounds. In April four (4) and in November one (1) workshop applications were approved.

This leaves provisions for five (5) out of ten (10) workshops (each € 14.000) unused.

13 Organizational expenses	2020	Budget 2020 €	€
Research committee/ director	11.313	16.000	1 5.1 05
Audit costs and payroll accounting	9.966	10.000	8.228
Website and IT	2.764	50 0	1.017
Executive Committee	578	3.000	3.186
Marketing	3.669	5.000	4.282
Congress expenses	705	3.000	5.805
Office costs - Baarn	4.670	4.300	1.834
Bank expenses	835	-	1.407
Travelling expenses	2.307	-	2.988
Insurance premium	558	-	513
Workshop asssistents	-	3.000	-
Other	631	2.500	-
	37.996	47.300	44.365

Baarn, May 31, 2021 European Neuro Muscular Centre

Dr. A.I.M. Breukel-van der Kooi Managing Director



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INDEPENDENT AUDITOR'S REPORT

To: The management and board of European Neuro Muscular Centre

A. Report on the audit of the financial statements 2020 included in the annual report

Our opinion

We have audited the financial statements 2020 of European Neuro Muscular Centre, based in Baarn.

In our opinion the accompanying financial statements give a true and fair view of the financial position of European Neuro Muscular Centre as at 31 December 2020, and of its result for 2020 in accordance with the Guideline for annual reporting C1 'Small- sized-not-for-profit organisations' of the Dutch Accounting Standards Board.

The financial statements comprise:

- 1 the balance sheet as at 31 December 2020;
- 2 the profit and loss account for 2020;
- 3 the notes comprising a summary of the accounting policies and other explanatory information.

Basis for our opinion

We conducted our audit in accordance with Dutch law, including the Dutch Standards on Auditing. Our responsibilities under those standards are further described in the 'Our responsibilities for the audit of the financial statements' section of our report.

We are independent of European Neuro Muscular Centre in accordance with the *Verordening inzake de onafhankelijkheid van accountants bij assurance-opdrachten (ViO)*, Code of Ethics for Professional Accountants, a regulation with respect to independence) and other relevant independence regulations in the Netherlands. Furthermore we have complied with the *Verordening gedrags- en beroepsregels accountants* (VGBA, Dutch Code of Ethics).

We believe the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

B. Report on the other information included in the annual report

In addition to the financial statements and our auditor's report thereon, the annual report contains other information that consists of:

The Impact report.

Based on the following procedures performed, we conclude that the other information is consistent with the financial statements and does not contain material misstatements.





We have read the other information. Based on our knowledge and understanding obtained through our audit of the financial statements or otherwise, we have considered whether the other information contains material misstatements.

By performing these procedures, we comply with the requirements of the Dutch Standard 720. The scope of the procedures performed is substantially less than the scope of those performed in our audit of the financial statements.

Management is responsible for the preparation of the other information, including the Impact report in accordance with the Guideline for annual reporting C1 'Small-sized-not-for-profit organisations' of the Dutch Accounting Standards Board.

C. Description of responsibilities regarding the financial statements

Responsibilities of management for the financial statements

Management is responsible for the preparation and fair presentation of the financial statements in accordance with the Guideline for annual reporting C1 'Small-sized-not-for-profit organisations' of the Dutch Accounting Standards Board. Furthermore, management is responsible for such internal control as management determines is necessary to enable the preparation of the financial statements that are free from material misstatement, whether due to fraud or error.

As part of the preparation of the financial statements, management is responsible for assessing the company's ability to continue as a going concern. Based on the financial reporting framework mentioned, management should prepare the financial statements using the going concern basis of accounting unless management either intends to liquidate the company or to cease operations, or has no realistic alternative but to do so.

Management should disclose events and circumstances that may cast significant doubt on the company's ability to continue as a going concern in the financial statements.

Our responsibilities for the audit of the financial statements

Our objective is to plan and perform the audit assignment in a manner that allows us to obtain sufficient and appropriate audit evidence for our opinion.

Our audit has been performed with a high, but not absolute, level of assurance, which means we may not detect all material errors and fraud during our audit.

Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of these financial statements. The materiality affects the nature, timing and extent of our audit procedures and the evaluation of the effect of identified misstatements on our opinion.

We have exercised professional judgement and have maintained professional skepticism throughout the audit, in accordance with Dutch Standards on Auditing, ethical requirements and independence requirements. Our audit included e.g.:

- Identifying and assessing the risks of material misstatement of the financial statements,
 whether due to fraud or error, designing and performing audit procedures responsive to those
 risks, and obtaining audit evidence that is sufficient and appropriate to provide a basis for our
 opinion. The risk of not detecting a material misstatement resulting from fraud is higher than
 for one resulting from error, as fraud may involve collusion, forgery, intentional omissions,
 misrepresentations, or the override of internal control;
- Obtaining an understanding of internal control relevant to the audit in order to design audit procedures that are appropriate in the circumstances, but not for the purpose of expressing an opinion on the effectiveness of the company's internal control;
- Evaluating the appropriateness of accounting policies used and the reasonableness of accounting estimates and related disclosures made by management;



- Concluding on the appropriateness of management's use of the going concern basis of
 accounting, and based on the audit evidence obtained, whether a material uncertainty exists
 related to events or conditions that may cast significant doubt on the company's ability to
 continue as a going concern. If we conclude that a material uncertainty exists, we are required
 to draw attention in our auditor's report to the related disclosures in the financial statements
 or, if such disclosures are inadequate, to modify our opinion. Our conclusions are based on the
 audit evidence obtained up to the date of our auditor's report. However, future events or
 conditions may cause a company to cease to continue as a going concern;
- Evaluating the overall presentation, structure and content of the financial statements, including the disclosures; and
- Evaluating whether the financial statements represent the underlying transactions and events in a manner that achieves fair presentation.

We communicate with those charged with governance regarding, among other matters, the planned scope and timing of the audit and significant audit findings, including any significant findings in internal control that we identify during our audit.

Volendam, May 31, 2021

NBC Audit Services B.V.

W.J.T. Jonk RA