Financial accounts - December 31, 2021

European Neuro Muscular Centre

(a foundation under Dutch Law)

Lt. Gen. van Heutszlaan 6 3743 JN Baarn

Table of contents

	Page
Activity report	2
Financial statements	
Balance sheet as at December 31, 2021	3
Statement of income and expenses for the year 2021	4
Cash flow statement for the year 2021	5
Notes to the financial accounts	6
Notes to the balance sheet	9
Notes to the statement of activities	16

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, 2021

After proposal profit appropriation

	<u>31-12-2021</u> €	31-12-2020 €
1	-	4.990
2	631.374	573.745
	621 274	578.735
		378.733
3	414.717	356.625
4	182.029	185.622
5	34.628	36.488
	631.374	578.735
	3	1 - 2 631.374 631.374 631.374 3 414.717 4 182.029

Statement of income and expenses for the year 2021

Income Member contributions Associated member contributions Company Forum contributions Other contributions Total income	2021 € 231.000 10.000 84.204 5.000 330.204	Budget 2021 € 231.000 15.000 85.000 5.000 336.000	2020 € 231.000 10.000 75.791 1.000 317.791
Expenses			
Personnel expenses	183.075	177.500	156.237
Housing expenses	11.574	11.300	11.326
Activity expenses	22.716	140.000	68.059
Organizational expenses	53.801	62.000	37.996
Total operating expenses	271.166	390.800	273.618
Operating result	59.038	-54.800	44.173
Interest income	-946	-1.000	-106
Net result	58.092	-55.800	44.067
Appropriation of result			
Development reserve	-	-	80.000
Development reserve - withdrawal	-20.746	-20.500	-3.652
Other free reserves	78.838	-35.300	-32.281
	58.092	-55.800	44.067

Cashflow statement for the year 2021

		2021		2020
	€	€	€	€
Operating result		59.038		44.173
Adjustment for:				
Movement in provisions		-3.593		29.860
Changes in working capital:				
Other accounts receivable	4.990		22.039	
Current liabilities	-1.860		54	
		3.130		22.093
Cash flow from operating activities		58.575		96.126
Interest received	-	-946		-106
Cash movement	=	57.629	;	96.020
Balance as at beginning of the financial year		573.745		477.725
Movement during the financial year	_	57.629		96.020
Balance at the end to the financial year	<u>-</u>	631.374		573.745

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

•	A.I		
1	Other	receival	oies

	31-12-2021	31-12-2020
	€	€
Other receivables and accrued assets		
Contributions	-	4.124
Prepaid expenses		866
	_	4.990
		4.990
2 Cash at banks		
ING Top rente 68.44.14.880	375.804	376.750
ING RC 68.44.14.880	179.992	196.995
ING RC 0008.2897.39	75.578	
	631.374	573.745
3 Equity		
Continuity reserve	200.000	200.000
Development reserve	55.602	76.348
Other (free) reserves	159.115	80.277
	414.717	356.625

A minimum of € 25.000 will remain in Other free reserves to be able to cover unexpected costs.

	2021	2020
	€	€
Continuity reserve		
Balance as at January 1	200.000	200.000
Appropriation of result		
Balance as at December 31	200.000	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.

2021	2020
€	€
76.348	-
-	80.000
-20.746	-3.652
55.602	76.348
	€ 76.348 - -20.746

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.

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

	2021	2020
	€	€
Other free reserves		
Balance as at January 1	80.277	112.558
Appropriation of result	78.838	-32.281
Balance as at December 31	159.115	80.277

The operational result of \in 58.366 is added to the Other free reserves (01-01-2021: \in 80.277). Since an amount of \in 20.746 was used in 2021 of the Developmental reserve, this amount can also be added to the Other free reserves, resulting in a balance of \in 159.389. The total appropriation of result therefore is \in 78.838.

4 Workshop provisions	000
	000
Workshop 248 - 1	
Workshop 249 - 1	.995
Workshop 250 -	849
·	.000
Workshop 252 - 3	.778
Workshop 253 14.732 15	.000
Workshop 254 15.000 15	.000
Workshop 255 14.977 15	.000
Workshop 256 5.231 15	.000
Workshop 257 15.000 15	.000
Workshop 258 15.000 15	.000
Workshop 259 - 15	.000
Workshop 260 14.000 14	.000
Workshop 261 14.000 14	.000
Workshop 262 14.000 14	.000
Workshop 263 14.000 14	.000
Workshop 264 4.089 14	.000
Workshop 265 14.000	-
Workshop 266 14.000	-
Workshop 267 14.000	
	.622

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.

The average workshop costs were lower in 2021 due to the organisation of mainly virtual meetings. Almost all virtual workshops will be held face-to-face in 2022 and the expected workshop costs are again € 14.000.

	2021	2020
	€	€
Workshop 248		
Balance as at January 1	1.000	1.416
Provision	-	290
Expenses paid in the bookyear	-130	-706
Not declared	-870	
Balance as at December 31		1.000

	2021	2020
	2021	
Workshop 249	Č	C
Balance as at January 1	1.995	13.398
Expenses paid in the bookyear	-300	-11.403
Not declared	-1.695	-
Balance as at December 31		1.995
Workshop 250		
Balance as at January 1	849	1.287
Expenses paid in the bookyear	-	-438
Not declared	-849	<u> </u>
Balance as at December 31	-	849
Workshop 251	2 000	11.667
Balance as at January 1	3.000	11.667
Provision	1 420	962
Expenses paid in the bookyear Not declared	-1.420	-9.629
Not declared	-1.580	·
Balance as at December 31	_	3.000
		= ====
Workshop 252		
Balance as at January 1	3.778	15.000
Expenses paid in the bookyear	-207	-11.222
Not declared	-3.571	-
Balance as at December 31		3.778
Workshop 253		
Balance as at January 1	15.000	15.000
Expenses paid in the bookyear	-268	<u> </u>
	4 4 722	45.000
Balance as at December 31	14.732	15.000
Workshop 254		
Balance as at January 1	15.000	15.000
Expenses paid in the bookyear	13.000	13.000
Expenses paid in the bookyear		·
Balance as at December 31	15.000	15.000
Workshop 255		
Balance as at January 1	15.000	15.000
Expenses paid in the bookyear	-23	
Balance as at December 31	14.977	15.000

	2021	2020
	€	€
Workshop 256		
Balance as at January 1	15.000	15.000
Expenses paid in the bookyear	-9.769	
Balance as at December 31	5.231	15.000
Workshop 257		
Balance as at January 1	15.000	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	15.000
Expenses paid in the bookyear	-	-
, ,		
Balance as at December 31	15.000	15.000
Workshop 259		
Balance as at January 1	15.000	15.000
Not declared	-15.000	-
Balance as at December 31		15.000
Workshop 260		
Balance as at January 1	14.000	-
Provision	-	14.000
Expenses paid in the bookyear		
Balance as at December 31	14.000	14.000
Workshop 261		
Balance as at January 1	14.000	-
Provision	-	14.000
Expenses paid in the bookyear		-
Balance as at December 31	14.000	14.000
Workshop 262		
Balance as at January 1	14.000	-
Provision	-	14.000
Expenses paid in the bookyear		
Balance as at December 31	14.000	14.000
Datation as at December 31	14.000	14.000

	2021	2020
	€	€
Workshop 263	14.000	
Balance as at January 1 Provision	14.000	14.000
Expenses paid in the bookyear	_	-
zaponoso para meno zoonyosa		
Balance as at December 31	14.000	14.000
Workshop 264		
Balance as at January 1	14.000	-
Provision	2.580	14.000
Expenses paid in the bookyear	-12.491	
Balance as at December 31	4.089	14.000
Workshop 265		
Balance as at January 1	-	-
Provision	14.000	-
Expenses paid in the bookyear		
Balance as at December 31	14.000	
Workshop 266		
Balance as at January 1	-	-
Provision	14.000	-
Expenses paid in the bookyear		
Balance as at December 31	14.000	
Workshop 267		
Balance as at January 1	-	-
Provision	14.000	-
Expenses paid in the bookyear		
Balance as at December 31	14.000	
Current linkilities		
Current liabilities	31-12-2021	31-12-2020
	€	€
5 Other payables		
Rental and service charges SN	11.574	11.574
Creditors	2.608	1.790
Accounting and audit fees	6.734	6.713
Wage tax	7.484	9.624
Pension premium	-	2.000
Accrued holiday allowance	4.948	4.787
Net wages	80	-
Other amounts payable	1.200	
	34.628	36.488

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 lower as budgeted. Therefore, ENMC will have extra Other free reserves available to manage any unexpected expenditures in the following year.

ENMC is organizing hybrid meetings in the upcoming months to enable a participation for all participants. This technical set-up brings additional costs with it.

Notes to the statements of activities

		Budget	
	2021	2021	2020
	€	€	€
6 Member contributions			
Deutsche Gesellschaft für Muskelkranke (Germany)	33.000	-	33.000
Muscular Dystrophy UK (United Kingdom)	33.000	-	33.000
Muskelsvindfonden (Denmark)	33.000	-	33.000
Fondazione Telethon (Italy)	33.000	-	33.000
Association Française contre les Myopathies (France)	33.000	-	33.000
Schweizerische Stiftung für die Erforschung der	33.000		33.000
Muskelkrankheiten (Switzerland)		-	
Prinses Beatrix Spierfonds (The Netherlands)	16.500	-	16.500
Spierziekten Nederland (The Netherlands)	16.500	-	16.500
Total budget member contributions		231.000	
	231.000	231.000	231.000
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	-	10.000
Amicus Therapeutics	5.000	-	5.000
Ionis Pharmaceuticals	4.204	-	4.124
Biogen	-		6.667
Novartis (AveXis)	20.000		5.000
WallacOy/PerkinElmer	5.000		5.000
Total budget Company Forum		85.000	
	84.204	85.000	75.791

	Budget		
	2021	2021	2020
	€	€	€
9 Other contributions			
SMA Europe (workshop 264)	5.000	-	-
Philips (workshop 252)	-	-	1.000
Total budget other contributions		5.000	
	5.000	5.000	1.000

In 2021, 27% of the total income was received from companies and 73% 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	130.980	-	105.894
Social charges	20.866	-	19.327
Pensions	16.004	-	20.580
Movement to accrual holiday allowance	9.253	-	7.775
Insurance sickleave current year	3.761	-	1.680
Other personnel expenses	2.211	-	981
Total budget salaries (including workshop assistents)		177.500	
	183.075	177.500	156.237

Average numbers of employees

During the year 2021 ENMC employed, converted to full-time equivalents, on average 2,0 employees (2020: average 1,5).

11 Housing expenses

Office rental and services	11.574	11.300	11.326

		Budget	
	2021	2021	2020
	€	€	€
12 Activity expenses			
Workshop 247	384		
Workshop 248	-		290
Workshop 251	-		962
Workshop 260			14.000
Workshop 261			14.000
Workshop 262			14.000
Workshop 263			14.000
Workshop 264	2.580		14.000
Workshop 265	14.000		
Workshop 266	14.000		
Workshop 267	14.000		
Developmental projects	1.316		3.652
Additional amounts previous workshops	-	-	794
Non-declared amounts previous years	-	-	-7.639
Total budget activity expenses	-23.564	140.000	
	22.716	140.000	68.059

In 2021, ENMC made a budget provision for ten (10) workshops to be approved in the two review rounds. In April no workshop application was received, in November three (3) workshop applications were approved.

This leaves provisions for seven (7) out of ten (10) workshops (each € 14.000) unused.

		Budget	
	2021	2021	2020
	€	€	€
13 Organizational expenses			
Research committee/ director	17.109	-	11.313
Audit costs and payroll accounting	5.154	-	7.834
Accounting costs	2.420	-	2.132
Website and IT	7.549	-	2.764
Executive Committee	7.166	-	578
Marketing	2.003	-	3.669
Congress expenses	1.865	-	705
Office costs - Baarn	4.899	-	4.670
Bank expenses	921	-	835
Travelling expenses	2.418	-	2.307
Insurance premium	842	-	558
Workshop asssistents	-	-	-
Ohter	1.455	-	631
Total budget organizational expenses		62.000	
	53.801	62.000	37.996

Baarn, May 24, 2022 European Neuro Muscular Centre

A.G.H. Méjat J.C. Rahbek

A.T. Ambrosini A. von Moers

R. Willmann A.I.M. Breukel-van der Kooi

I. Meijer K.H. Adcock

S.A. van den Berge



KANTOORADRES
JULIANAWEG 190A
1131 DL VOLENDAM
POSTADRES
POSTBUS 145
1130 AC VOLENDAM
TELEFOON
(0299) 657060
FAX
(0299) 652373
E-MAIL
INFO@NBCVANROEMBURG.NL
INTERNET

Stichting European Neuro Muscular Centre Lt. Gen. Van Heutszlaan 6 3743 JN Baarn

INDEPENDENT AUDITOR'S REPORT

To: The management and board of European Neuro Muscular Centre

A. Report on the audit of the financial statements 2021 included in the annual report

Our opinion

We have audited the financial statements 2021 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 2021, and of its result for 2021 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 2021;
- 2 the profit and loss account for 2021;
- 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 24, 2022

NBC Audit Services B.V.

W.J.T. Jonk RA