# Financial accounts - December 31, 2022

**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, 2022

After proposal profit appropriation

ASSETS		<u>31-12-2022</u> €	31-12-2021 €
Current assets			
Other receivables	1	10.000	-
Cash at banks	2	659.123	631.374
		669.123	631.374
EQUITY AND LIABILITIES			
Equity	3	497.321	414.717
Provisions			
Workshop provisions	4	124.951	182.029
Current liabilities			
Other payables	5	46.851	34.628_
		669.123	631.374

# Statement of income and expenses for the year 2022

€   €	2021
Income Member contributions 231.000 231.000 231	€
202,000	
Associated member contributions 20.000 20.000 10	.000
	.000
Company Forum contributions 124.940 99.565 84.	.204
Other contributions 57.659 20.000 5	.000
<b>Total income</b> 433.599 <i>370.565</i> 330	.204
_	
Expenses  Description of the second of the s	
	.075
	.574
	.716
	.801
Total operating expenses         349.393         377.000         271.	.166
<b>Operating result</b> 84.206 -6.435 59.	.038
Interest income -1.602 -946	-946
Net result 82.604 -7.381 58.	.092
Appropriation of result	
	.746
	.838
82.6047.38158.	.092

# Cashflow statement for the year 2022

		2022		2021
	€	€	€	€
Operating result		84.206		59.038
Adjustment for:				
Movement in provisions		-57.078		-3.593
Changes in working capital:				
Other accounts receivable	-10.000		4.990	
Current liabilities	12.223		-1.860	
	·	2.223		3.130
Cash flow from operating activities		29.351		58.575
Interest received	7_	-1.602	9	-946
Cash movement	=	27.749		57.629
Balance as at beginning of the financial year		631.374		573.745
Movement during the financial year	8 <u>1</u>	27.749	à	57.629
Balance at the end to the financial year	=	659.123		631.374

#### 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.

In addition to workshops, the ENMC set up a Next Generation Programme to help young, bright talent enter the neuromuscular field and prepare for a leadership role in the future. This programme was initiated to motivate young and talented clinicians and researchers stay in the field of neuromuscular diseases.

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.

### Disclosure of estimates

In applying the principles and policies for drawing up the financial statements, the directors of European Neuro Muscular Centre make different estimates and judgments that may be essential to the amounts disclosed in the financial statements. If it is necessary in order to provide the transparency, the nature of these estimates and judgments, including related assumptions, is disclosed in the notes to the relevant financial statement item.

# 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
---------------------

	31-12-2022	31-12-2021 €
Other receivables and accrued assets		
Contributions	10.000	_
Prepaid expenses	_	_
	-	-
	10.000	
2 Cash at banks		
ING Top rente 68.44.14.880	374.657	375.804
ING RC 68.44.14.880	265.075	<b>17</b> 9.992
ING RC 0008.2897.39	19.391	<b>7</b> 5.578
	659.123	631.374
3 Equity		
Continuity reserve	200.000	200.000
Developmental reserve	_	55.602
Transitional reserve	170.000	_
Global Travel Fund	100.000	-
Other (free) reserves	27.321	159.115
	3 <del> </del>	
	497.321	414.717
	Н	

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

	2022	2021
	€	€
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 was set on € 200.000 by the Executive Committee in 2016, which is the amount necessary to keep the office running and perform the approved workshops for one year.

	€	€
Developmental reserve (special-purpose reserve)		
Balance as at January 1	55.602	76.348
Appropriation of result: Expenses paid in the bookyear	-20.195	-20.746
Transfer to Other free reserves	-35.407	
		55.602

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. The developmental actions have take place in 2021 and 2022 and this reserve is no longer needed. The Developmental reserve ends on 31 December 2022 at € 35.407, which will be completely transferred to the Other free reserves.

	2022	2021
Transitional reserve	Č	e
Balance as at January 1	-	-
Formation Transitional reserve (from Other free reserves)	170.000	
Balance as at December 31	170.000	

With the expansion of the team, the personnel expenses are substantially higher than in previous years. Until new income is generated for the long-term € 170.000 from the Other free reserves can be used for these new infrastructural expenses in 2023, 2024 and 2025.

	2022	2021
	€	€
Global Travel Fund		
Balance as at January 1	-	_
Formation Global Travel Fund (from Other free reserves)	100.000	
Balance as at December 31	100.000	

A Global Travel Fund may be installed as a consequence of the new long-term vision of the ENMC: a European foundation with a worldwide reach. For three year (2024-2026), an amount of € 100.000 is available and will be transferred from the Other free reserves to this Global Travel Fund. ENMC will reimburse travel of participants from non-ENMC member European countries with a max of € 300 and of participants from continents other than Europe to a max of € 1.000, to make it possible that NMD experts from all over the world attend ENMC workshops.

	2022	2021
	€	€
Other free reserves		
Balance as at January 1	159.115	80.277
Release Developmental reserve	35.407	-
Formation Transitional reserve	-170.000	-
Formation Global Travel Fund	-100.000	-
Appropriation of result	102.799	78.838
Balance as at December 31	27.321	159.115
The appropriation of result is explained on page 4.		
	31-12-2022	31-12-2021
	€	€
4 Workshop provisions		
Workshop 253	1.000	14.732
Workshop 254	_	15.000
Workshop 255	4.240	<b>14</b> .977
Workshop 256	-	5.231
Workshop 257	13.412	15.000
Workshop 258	8.028	15.000
Workshop 260	4.055	14.000
Workshop 261	3.508	14.000
Workshop 262	8.726	14.000
Workshop 263	2.000	14.000
Workshop 264	1.229	4.089
Workshop 265	3.500	14.000
Workshop 266	4.500	14.000
Workshop 267	1.200	14.000
Workshop 268	2.200	-
Workshop 269	25.353	-
Workshop 270	14.000	-
Workshop 271	14.000	-
Workshop 272	14.000	-
	124.951	182.029

	2022	2021
Workshop 253		
Balance as at January 1	14.732	15.000
Additional provision	2.829	-
Expenses paid in the bookyear	-16.561	-268
Balance as at December 31	1.000	14.732
Workshop 254 (administratively closed)		
Balance as at January 1	15.0 <b>00</b>	15.000
Not declared	-15.000	-
Balance as at December 31	-	15.000
Workshop 255		
Balance as at January 1	14.977	15.000
Expenses paid in the bookyear	10.737	-23
Balance as at December 31	4.240	14.977
Workshop 256 (administratively closed)		
Balance as at January 1	5.231	15.000
Expenses paid in the bookyear	-271	-9.769
Not declared	-4.960	
Balance as at December 31		5.231
Workshop 257		
Balance as at January 1	15.000	15.000
Third party contributions	9.427	-
Expenses paid in the bookyear	-11.015	-
	*	<del></del>
Balance as at December 31	13.412	15.000
Workshop 258		
Balance as at January 1	15.000	15.000
Expenses paid in the bookyear	-6.972	-
Balance as at December 31	8.028	15.000
Workshop 260		
Balance as at January 1	14.000	14.000
Third party contributions	5.600	-
Expenses paid in the bookyear	-15.545	
Balance as at December 31	4.055	14.000
Workshop 261		
Balance as at January 1	14.000	14.000
Third party contributions	5.836	-
Expenses paid in the bookyear	16.328	
Balance as at December 31	3.508	14.000

	2022	2021
	€	€
Workshop 262		
Balance as at January 1	14.000	14.000
Provision	-	-
Expenses paid in the bookyear	-5.274	
Balance as at December 31	8.726	14.000
Workshop 263		
Balance as at January 1	14.000	14.000
Additional provision	292	
Expenses paid in the bookyear	-12.292	-
Balance as at December 31	2.000	14.000
Workshop 264		
Balance as at January 1	4.089	14.000
Additional provision	-	2.580
Expenses paid in the bookyear	2.860	-12.491
Balance as at December 31	1.229	4.089
Markehan 265		
Workshop 265 Balance as at January 1	14.000	
Provision	14.000	14.000
Additional provision	7.011	14.000
Expenses paid in the bookyear	-17.511	_
•		
Balance as at December 31	3.500	14.000
Workshop 266		
Balance as at January 1	14.000	-
Provision	-	14.000
Additional provision	2.144	-
Third party contributions	4.763	-
Expenses paid in the bookyear	16.407	
Balance as at December 31	4.500	14.000
Workshop 267		
Balance as at January 1	14.000	_
Provision	- 11000	14.000
Additional provision	3.049	
Expenses paid in the bookyear	15.849_	
Balance as at December 31	1.200	14.000

	2022	2021
	€	€
Workshop 268		
Balance as at January 1	_	-
Provision	14.000	-
Additional provision	7.238	
Expenses paid in the bookyear	19.038_	
Balance as at December 31	2.200	
Workshop 269		
Balance as at January 1		_
Provision	_	_
Third party contributions	29.559	
Expenses paid in the bookyear	-4.206	_
anpointed para in the bookyear	-4.200	3
Balance as at December 31	25.353	-
Workshop 270		
Balance as at January 1	-	_
Provision	14.000	_
		-
Balance as at December 31	14.000	<u> </u>
Workshop 271		
Balance as at January 1	-	_
Provision	14.000	_
		-
Balance as at December 31	14.000	
Workshop 272		
Balance as at January 1	_	
Provision	14.000	-
TOVISION	14.000	-
Balance as at December 31	14.000	

# **Current liabilities**

	31-12-2022	31-12-2021
	€	€
5 Other payables		
D. Maryland C. J. Com		
Rental and service charges SN	11.5 <b>74</b>	11.574
Creditors	4.682	2.608
Accounting and audit fees	7.036	6.734
Wage tax	12.985	7.484
Accrued holiday allowance	4.37 <b>4</b>	4.948
Net wages	_	80
Research Committee	5.000	_
Other amounts payable	1.200	1.200
	46.851	34.628

# Notes to the statements of activities

6 Member contributions	2022	Budget €	2021
Deutsche Gesellschaft für Muskelkranke (Germany)	33.000		22.000
Muscular Dystrophy UK (United Kingdom)	33.000		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)			55.555
Prinses Beatrix Spierfonds (The Netherlands)	16.500		16.500
Spierziekten Nederland (The Netherlands)	16.500		16.500
Total budget member contributions	<u>-</u>	231.000	-
	(	0	
	231.000	<u>231.000</u>	231.000
7 Associated member contributions			
Finnish Neuromuscular Association (Finland)	5.000		5.000
Österreichische Muskelforschung (Austria)	5.000		5.000
SMA Europe	5.000		5.000
World Duchenne Organisation	5.000		_
Total budget associated member contributions		20.000	_
	-		
	20.000		10.000
8 Company Forum contributions			
Sanofi	20.000		20.000
Roche	20.000		20.000
Lupin Neurosciences	10.000		10.000
Astellas/Audentes	19.960		-
Amicus Therapeutics	5.000		5.000
Ionis Pharmaceuticals	4.980		4.204
Biogen	20.000		-
Novartis	20.000		20.000
PerkinElmer/WallacOy	5.000		5.000
Total budget Company Forum	-	99.565	
	124.940	99.565	<u>84.204</u>

	2022	Budget 2022	2021
9 Other contributions	€	€	€
SMA Europe (workshop 264)	-		5.000
Amplo Biotechnology (workshop 260)	2.000		_
Argenx IIP B.V. (workshop 260)	3.600		-
Muscular Dystrophy Association (workshop 261)	5.836		-
CureLGMD2i, Limb Girdle Muscalar Dystrophy			
(workshop 257)	4.725		-
Facioscapulohumeral Muscular Dystrophy Society			
(workshop 268)	2.475		-
Parent Project Muscular Dystrophy (workshop 269)	<b>19.5</b> 59		-
CureLGMD2i, Limb Girdle Muscalar Dystrophy			
(workshop 257)	4.701		-
Edgewise Therapeutics (workshop 266)	4.763		-
Collaborative Trajectory Analysis Project c-TAP (workshop			
269)	10.000		_
Total budget other contributions	a	20.000	·
	57.659	20.000	5.000

In 2022, 31% of the total income was received from companies and 69% 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	147.932		130.980
Social charges	23.194		20.866
Pensions	19.572		16.004
Movement to accrual holiday allowance	10.773		9.253
Insurance personnel	10.171		3.761
Other personnel expenses	10.413		2.211
Total budget salaries (including workshop assistents)		165.500_	
			0:
	222.055	165.500	183.075
Received payment from sick leave insurance	58.771		
	163.284	165.500	183.075

# Average numbers of employees

During the year 2022 ENMC employed, converted to full-time equivalents, on average 2,2 employees (2021: average 2,0).

# 11 Housing expenses

Office rental and services	11.574	11.500	11.574
	-		

12 Activity expenses	€	Budget €	2021 €
Workshop 247	_		384
Workshop 253	2,829		504
Workshop 257	9.427		_
Workshop 260	5.600		-
Workshop 261	5.836		
Workshop 263	292		_
Workshop 264	-		2.580
Workshop 265	7.011		14.000
Workshop 266	6.907		14.000
Workshop 267	3.049		14.000
Workshop 268	21.238		-
Workshop 269	29.559		-
Workshop 270	14.000		-
Workshop 271	14.000		-
Workshop 272	14.000		-
Developmental projects	-		1.316
Non-declared amounts	-19.960		-
Total budget activity expenses		140.000	-23.564
	113.788	140.000	22.716

In 2022, ENMC made a budget provision for ten (10) workshops to be approved in the two review rounds. In April four (4) workshop applications and in November three (3) workshop applications were received. In total, five (5) applications were approved during 2022 for execution (71% approval rate).

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

		Budget	
	2022	2022	2021
	€	€	€
13 Organizational expenses			
Research committee/director	12.808		17.109
Audit costs and payroll accounting	7.928		<b>5</b> .154
Accounting costs	2.698		2.420
Website and IT	7.874		7.549
Executive Committee	2.054		7.166
Marketing	5.830		2.003
Congress expenses	2.471		1.865
Office costs - Baarn	14.783		4.899
Bank expenses	959		921
Travelling expenses	1.605		2.418
Insurance premium	834		842
Other	903		1.455
Total budget organizational expenses		60.000	
	60.747	60.000	53.801

Baarn, May 25, 2023 European Neuro Muscular Centre

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



Stichting European Neuro Muscular Centre Lt. Gen. Van Heutszlaan 6 3743 JN Baarn KANTODRADRES
JULIANAWEG 19DA
1131 DL VOLENDAM
POSTADRES
POSTEUS 145
1130 AC VOLENDAM
TELEFOON
(0299) 67 99 99
E-MAIL
INFO@NBCAUDITSERVICES, NL

#### **INDEPENDENT AUDITOR'S REPORT**

To: The management and board of European Neuro Muscular Centre

# A. Report on the audit of the financial statements 2022 included in the annual report

## **Our opinion**

We have audited the financial statements 2022 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 2022, and of its result for 2022 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 2022;
- 2 the profit and loss account for 2022;
- 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 25, 2023

NBC Audit Services B.V.

W.J.T. Jonk RA