

FINANCIAL ACCOUNTS - December 31, 2015

**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.

Balance sheet as at 31 December 2015*After proposal profit appropriation*

		<u>31-12-2015</u>	<u>31-12-2014</u>
		€	€
ASSETS			
Current assets			
<i>Other receivables</i>	1	18.113	32.750
<i>Cash at banks</i>	2	518.654	427.031
		<u>536.767</u>	<u>459.781</u>
EQUITY AND LIABILITIES			
Equity	3	357.743	424.941
Provisions			
Workshop provisions	4	147.872	-
Current liabilities			
Other payables	5	31.152	34.840
		<u>536.767</u>	<u>459.781</u>

Statement of income and expenses for the year 2015

		<u>2015</u>	<i>Budget</i> <u>2015</u>	<u>2014</u>
		€	€	€
Income				
Member contributions	6	210.000	<i>210.000</i>	210.000
Associated member contributions	7	5.000	<i>10.000</i>	5.000
Company Forum contributions	8	48.333	<i>50.000</i>	-
Other contributions	9	40.309	<i>25.000</i>	88.690
Total income		<u>303.642</u>	<u><i>295.000</i></u>	<u>303.690</u>
Expenses				
Personnel expenses	10	115.529	<i>128.000</i>	104.920
Housing expenses	11	11.346	<i>12.000</i>	11.000
Activity expenses	12	196.272	<i>135.000</i>	80.401
Organizational expenses	13	50.778	<i>49.000</i>	40.732
Total operating expenses		<u>373.925</u>	<u><i>324.000</i></u>	<u>237.053</u>
Operating result		-70.283	<i>-29.000</i>	66.637
Interest income		3.085	<i>1.000</i>	3.749
Net result		<u>-67.198</u>	<u><i>-28.000</i></u>	<u>70.386</u>
		<u>2015</u>		<u>2014</u>
		€		€
Appropriation of result				
Continuity reserve		200.000		-
Other free reserves		<u>-267.198</u>		<u>70.386</u>
		<u>-67.198</u>		<u>70.386</u>

Cash flow statement for the year 2015

The cash at banks have increased in the year 2015 by approximately € 92.000.

This increase is due to cash flows from operating activities as shown in the following cash flow statement.

x 1.000	2015		2014	
	€	€	€	€
Operating result		-70		67
Adjustments for:				
Movement in provisions		148		-
Changes in working capital:				
Other accounts receivable	15		14	
Current liabilities	-4		-32	
		11		-18
Cash flow from operating activities		<u>89</u>		<u>49</u>
Interest received		<u>3</u>		<u>3</u>
		<u>92</u>		<u>52</u>
Cash movements		<u><u>92</u></u>		<u><u>52</u></u>

Turnover cash movement and cash equivalents

Balance as at beginning of financial year	427	375
Movements during financial year	<u>92</u>	<u>52</u>
Balance at financial year end	<u><u>519</u></u>	<u><u>427</u></u>

In 2015 an operating result of approximately -/- € 70.000 was realised. Provisions for expected workshop expenses were created in 2015 for the amount of approximately € 148.000. In other accounts receivable approximately € 15.000 less was recorded than at the end of 2014 and approximately € 4.000 less was recorded in current liabilities at the end of 2015. This results in a cash flow from operating activities of approximately € 89.000.

Taking into account the interest income received of approximately € 3.000, a total cash flow movement of approximately € 92.000 was realised during 2015.

Notes to the financial accounts

General

This report was prepared in accordance with Guideline 640 for the Reporting of Non-profit-organizations as published by the Dutch Accounting Standards Board (Raad voor de Jaarverslaggeving). The financial accounts are drawn up in Euros.

Changes in accounting policies

As mentioned above, this report was prepared in accordance with Guideline 640. In prior years the financial accounts were compiled in accordance with accounting principles generally accepted in The Netherlands. This change in accounting policy has no financial impact on the figures of previous year(s).

The ENMC changed the budgeting system regarding the processing of the workshop costs as per this book year 2015. The majority of the costs of workshops are now accounted for in the year of approval by the Executive Committee. The costs are included in the activity expenses and a provision is created in the balance sheet for an average amount of workshop costs (calculated on a historical basis, currently € 13.000 per workshop). In the year that the workshop is closed and it is expected that no further expenses will be received, the surplus or deficit is accounted for in the statement of income and expenses. This is different from the budgeting system in previous years (up to and including 2014), in which actual costs were taken into account after completing the workshops.

The rationale for changing this budgeting system is the following:

- 1) by approving a workshop application the ENMC commits itself to facilitate and organize the workshop in the future;
- 2) there is a more than 50% likelihood that this obligation will become effective as is known from past ENMC workshops and
- 3) the ENMC can estimate the costs for a workshop that is being approved quite accurately.

In addition, provisions give a transparent and current insight into the activities of the foundation and into the use of promised co-sponsor funds and member contributions received in that same book year.

Activities

The European Neuromuscular 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 development, prevention 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 by a number of National Patient Associations for neuromuscular diseases in Europe and other related organizations. The foundation has its statutory seat in Baarn and holds office in the building of Spierziekten Nederland.

Accounting policies in respect of the valuation of assets and liabilities

General

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

Accounts receivable

Upon initial recognition the receivables are valued at fair value and then valued at amortised cost. The fair value and amortized cost equal the face value. Provisions deemed necessary for possible bad debt losses are deducted. These provisions are determined by individual assessment of the 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

Upon initial recognition, current liabilities are stated at fair value and then valued at amortized cost.

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 (approved concerning the expenses of workshops and of the committed contributions of 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 workshop 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

Fixed assets

Current assets

1 Other receivables

	<u>31-12-2015</u>	<u>31-12-2014</u>
	€	€
<i>Other receivables and accrued assets</i>		
Other contributions	11.695	19.000
Company Forum contribution by Amicus Therapeutics	3.333	-
Bank interest	3.085	3.750
Member contributions	-	10.000
	<u>18.113</u>	<u>32.750</u>

2 Cash at banks

ING Top rente 68.44.14.880	471.272	317.523
ING RC 68.44.14.880	<u>47.382</u>	<u>109.508</u>
	<u>518.654</u>	<u>427.031</u>

	<u>31-12-2015</u>	<u>31-12-2014</u>
	€	€
3 Equity		
Continuity reserve	200.000	-
Other free reserves	<u>157.743</u>	<u>424.941</u>
	<u>357.743</u>	<u>424.941</u>
	<u>2015</u>	<u>2014</u>
	€	€
Continuity reserve		
Balance as at 1 January	-	-
Appropriation of result	<u>200.000</u>	-
Balance as at 31 December	<u>200.000</u>	<u>-</u>
Other free reserves		
Balance as at 1 January	424.941	354.555
Withdrawal of result (2014: appropriation)	<u>-267.198</u>	<u>70.386</u>
Balance as at 31 December	<u>157.743</u>	<u>424.941</u>

Provisions**4 Workshop provisions**

	<u>31-12-2015</u>	<u>31-12-2014</u>
	€	€
Workshop 210	1.424	-
Workshop 211	4.762	-
Workshop 212	5.937	-
Workshop 214	9.246	-
Workshop 215	9.503	-
Workshop 216	13.000	-
Workshop 217	13.000	-
Workshop 218	13.000	-
Workshop 219	13.000	-
Workshop 220	13.000	-
Workshop 221	13.000	-
Workshop 222	13.000	-
Workshop 223	13.000	-
Workshop 224	13.000	-
	<u>147.872</u>	<u>-</u>

Currently the expected costs per approved workshop are € 13.000.

Concerning the workshops 210 - 215, costs already have been made and paid in 2015.

For workshop 213 the actual expenses exceeded the provision amount of € 13.000. Therefore no provision remains at the end of 2015 and the additional costs are included in the 2015 activity expenses.

	<u>2015</u>	<u>2014</u>
	€	€
Workshop 210		
Balance as at 1 January	-	-
Provision	1.424	-
Balance as at 31 December	<u>1.424</u>	<u>-</u>
Workshop 211		
Balance as at 1 January	-	-
Provision	4.762	-
Balance as at 31 December	<u>4.762</u>	<u>-</u>

	<u>2015</u>	<u>2014</u>
	€	€
Workshop 212		
Balance as at 1 January	-	-
Provision	<u>5.937</u>	-
Balance as at 31 December	<u><u>5.937</u></u>	<u><u>-</u></u>
Workshop 214		
Balance as at 1 January	-	-
Provision	<u>9.246</u>	-
Balance as at 31 December	<u><u>9.246</u></u>	<u><u>-</u></u>
Workshop 215		
Balance as at 1 January	-	-
Provision	<u>9.503</u>	-
Balance as at 31 December	<u><u>9.503</u></u>	<u><u>-</u></u>
Workshop 216		
Balance as at 1 January	-	-
Provision	<u>13.000</u>	-
Balance as at 31 December	<u><u>13.000</u></u>	<u><u>-</u></u>
Workshop 217		
Balance as at 1 January	-	-
Provision	<u>13.000</u>	-
Balance as at 31 December	<u><u>13.000</u></u>	<u><u>-</u></u>
Workshop 218		
Balance as at 1 January	-	-
Provision	<u>13.000</u>	-
Balance as at 31 December	<u><u>13.000</u></u>	<u><u>-</u></u>
Workshop 219		
Balance as at 1 January	-	-
Provision	<u>13.000</u>	-
Balance as at 31 December	<u><u>13.000</u></u>	<u><u>-</u></u>

	<u>2015</u>	<u>2014</u>
	€	€
<i>Workshop 220</i>		
Balance as at 1 January	-	-
Provision	<u>13.000</u>	-
Balance as at 31 December	<u><u>13.000</u></u>	<u><u>-</u></u>
<i>Workshop 221</i>		
Balance as at 1 January	-	-
Provision	<u>13.000</u>	-
Balance as at 31 December	<u><u>13.000</u></u>	<u><u>-</u></u>
<i>Workshop 222</i>		
Balance as at 1 January	-	-
Provision	<u>13.000</u>	-
Balance as at 31 December	<u><u>13.000</u></u>	<u><u>-</u></u>
<i>Workshop 223</i>		
Balance as at 1 January	-	-
Provision	<u>13.000</u>	-
Balance as at 31 December	<u><u>13.000</u></u>	<u><u>-</u></u>
<i>Workshop 224</i>		
Balance as at 1 January	-	-
Provision	<u>13.000</u>	-
Balance as at 31 December	<u><u>13.000</u></u>	<u><u>-</u></u>

Current liabilities

	<u>31-12-2015</u>	<u>31-12-2014</u>
	€	€
5 Other payables		
Rental and service charges SN	11.000	11.000
Accounting and audit fees	7.550	6.750
Wage tax	6.461	5.784
Accrued holiday allowance	3.341	3.224
Joint meeting	1.800	-
Office costs	1.000	1.232
Workshops	-	6.850
	<u>31.152</u>	<u>34.840</u>

Notes to the statement of activities

	<u>2015</u>	<i>Budget</i> <u>2015</u>	<u>2014</u>
	€	€	€
6 Member contributions			
Deutsche Gesellschaft für Muskelkranke (Germany)	30.000	-	30.000
Muscular Dystrophy UK (United Kingdom)	30.000	-	30.000
Muskelsvindfondene (Denmark)	30.000	-	30.000
Telethon Foundation (Italy)	30.000	-	30.000
Association Française contre les Myopathies (France)	30.000	-	30.000
Schweizerische Stiftung für die Erforschung der Muskelkrankheiten (Switzerland)	30.000	-	30.000
Prinses Beatrix Spierfonds (The Netherlands)	15.000	-	15.000
Spierziekten Nederland (The Netherlands)	15.000	-	15.000
Total budget member contributions	-	<i>210.000</i>	-
	<u>210.000</u>	<u>210.000</u>	<u>210.000</u>
7 Associated member contributions			
Finnish Neuromuscular Association (Finland)	<u>5.000</u>	<u>10.000</u>	<u>5.000</u>
8 Company Forum contributions			
Genzyme Europe B.V.	20.000	-	-
Santhera Pharmaceuticals	15.000	-	-
PTC Therapeutics	10.000	-	-
Amicus Therapeutics	3.333	-	-
Total budget Company Forum	-	<i>50.000</i>	-
	<u>48.333</u>	<u>50.000</u>	-

9 Other contributions

	<u>2015</u>	<i>Budget</i> <u>2015</u>	<u>2014</u>
	€	€	€
RYR-1 Foundation	11.695	-	-
LGMD2i Research Fund	10.867	-	-
LFB Biomedicaments	3.000	-	-
AstraZenica	3.000	-	-
ATyr Pharma	2.975	-	-
A Foundation Building Strength for Nemaline Myopathy	2.206	-	-
Myositis UK	2.000	-	-
Roche	2.000	-	-
ZonMw	-	-	32.000
Genzyme Europe B.V.	-	-	20.000
American Muscular Dystrophy Association	-	-	13.255
GlaxoSmithKline Rare Diseases	-	-	6.306
SMA Europe	-	-	5.000
American Parent Project Muscular Dystrophy	-	-	3.735
Biomarin Europe Limited	-	-	2.000
Amicus Therapeutics	-	-	1.980
Other	2.566	-	4.414
Total budget other contributions	-	25.000	-
	<u>40.309</u>	<u>25.000</u>	<u>88.690</u>

10 Personnel expenses

	<u>2015</u>	<i>Budget</i> <u>2015</u>	<u>2014</u>
	€	€	€
Salaries	77.969	-	70.615
Social charges	14.205	-	12.811
Pensions	11.509	-	8.354
Movement to accrual holiday allowance	5.587	-	5.013
Insurance sickleave current year	2.598	-	3.727
Total budget salaries	-	<i>128.000</i>	-
Other including external services	3.661	-	4.400
	<u>115.529</u>	<u><i>128.000</i></u>	<u>104.920</u>

Average number of employees

During the year 2015 ENMC employed, converted to full-time equivalents, on average 1,3 employees with 2,0 employees in total (2014: idem).

	<u>2015</u>	<i>Budget</i> <u>2015</u>	<u>2014</u>
	€	€	€
11 Housing expenses			
Office rental and services	<u>11.346</u>	<u><i>12.000</i></u>	<u>11.000</u>

	<u>2015</u>	<i>Budget</i> <u>2015</u>	<u>2014</u>
	€	€	€
12 Activity expenses			
Workshop 204	-	-	15.497
Workshop 205	-	-	12.200
Workshop 206	-	-	16.667
Workshop 207	485	-	12.149
Workshop 208	-	-	12.197
Workshop 209	-	-	13.642
Workshop 210	13.000	15.000	-
Workshop 211	13.000	15.000	-
Workshop 212	13.000	15.000	-
Workshop 213	15.400	15.000	-
Workshop 214	13.000	15.000	-
Workshop 215	13.000	15.000	-
Workshop 216	13.000	15.000	-
Workshop 217	13.000	15.000	-
Workshop 218	13.000	15.000	-
Workshop 219	13.000	-	-
Workshop 220	13.000	-	-
Workshop 221	13.000	-	-
Workshop 222	13.000	-	-
Workshop 223	13.000	-	-
Workshop 224	13.000	-	-
Company Forum Costs	1.272	-	-
Non-declared amounts previous year	-2.885	-	-1.951
	<u>196.272</u>	<u>135.000</u>	<u>80.401</u>

Because of the change in the budgeting system 2015 has become a transitional year: in this year the activity expenses consist of the provisions for workshops approved in 2015 (new system) and the actual costs and provisions for workshops approved before 2015 (bringing the old workshops into the new system). This explains the higher costs in this transitional year compared with the activity expenses in the budget 2015, which were estimated on the old system. As a result, the negative net result will be balanced by the other free reserves, as was approved by the Executive Committee in 2015.

For the workshops approved in 2015 (215-224) a provision for the estimated amount of € 13.000,- per workshop has been created according to the new system. To bring workshops 210-214 (approved in 2014 and held in 2015) into the new system, a provision for these was also created for the estimated amount of € 13.000,- per workshop. When expenses are paid, they are paid from the provision; the remaining provision amount per workshop at 31 December 2015 is stated on page 11. For workshop 213 the actual expenses exceeded the provisioned amount and the additional costs are accounted for as activity expenses in 2015. For workshop 207 the actually paid costs in 2015 (€ 1.685) are above the estimated costs at the end of 2014 (€ 1.200 liability). The difference is accounted for as activity expenses in 2015.

	<u>2015</u>	<i>Budget</i> <u>2015</u>	<u>2014</u>
	€	€	€
13 Organizational expenses			
Research committee / director	17.639	<i>17.500</i>	18.829
Audit costs and salary administration	7.950	<i>6.500</i>	7.389
Website	6.522	<i>6.000</i>	2.326
Executive committee	5.743	<i>12.000</i>	2.371
Marketing	4.073	-	-
Congress expenses	3.021	-	3.752
Office costs - Baarn	2.987	<i>7.000</i>	2.414
Bank expenses	928	-	900
Travelling and hotel expenses	785	-	1.325
Insurance premium	586	-	838
Telephone expenses	544	-	588
	<u>50.778</u>	<u><i>49.000</i></u>	<u>40.732</u>

Baarn, April 21th, 2016
European Neuro Muscular Centre

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

INDEPENDENT AUDITOR'S REPORT

To: the management of European Neuro Muscular Centre

Report on the financial statements

We have audited the accompanying financial statements 2015 of European Neuro Muscular Centre, Baarn, which comprise the balance sheet as at 31 December 2015, the profit and loss account for the year then ended, the notes, comprising a summary of the accounting policies and other explanatory information.

Management's responsibility

Management is responsible for the preparation and fair presentation of these financial statements and for the preparation of the impact report, both in accordance with accounting principles for non-profit organisations generally accepted in the Netherlands (RJ640). Furthermore management is responsible for such internal control as it determines is necessary to enable the preparation of the financial statements that are free from material misstatement, whether due to fraud or error.

Auditor's responsibility

Our responsibility is to express an opinion on these financial statements based on our audit. We conducted our audit in accordance with Dutch law, including the Dutch Standards on Auditing. This requires that we comply with ethical requirements and plan and perform the audit to obtain reasonable assurance about whether the financial statements are free from material misstatement.

An audit involves performing procedures to obtain audit evidence about the amounts and disclosures in the financial statements. The procedures selected depend on the auditor's judgment, including the assessment of the risks of material misstatement of the financial statements, whether due to fraud or error.

In making those risk assessments, the auditor considers internal control relevant to the entity's preparation and fair presentation of the financial statements 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 entity's internal control. An audit also includes evaluating the appropriateness of accounting policies used and the reasonableness of accounting estimates made by management, as well as evaluating the overall presentation of the financial statements.

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

Opinion

In our opinion, the financial statements give a true and fair view of the financial position of European Neuro Muscular Centre as at December 31, 2015 and of its result for the year then ended in accordance with accounting principles for non-profit organisations generally accepted in the Netherlands (RJ640).

Hilversum, April 21th 2016

M&K Hilversum B.V.

w.s. A.J. de Quaasteniet RA