

Financial accounts - December 31, 2016

European Neuro Muscular Centre
(a foundation under Dutch Law)

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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 December 31, 2016*After proposal profit appropriation*

		<u>31-12-2016</u>	<u>31-12-2015</u>
		€	€
ASSETS			
Current assets			
Other receivables	1	4.440	18.113
Cash at banks	2	<u>485.613</u>	<u>518.654</u>
		<u>490.053</u>	<u>536.767</u>
EQUITY AND LIABILITIES			
Equity	3	329.858	357.743
Provisions			
Workshop provisions	4	130.659	147.872
Current liabilities			
Other payables	5	<u>29.536</u>	<u>31.152</u>
		<u>490.053</u>	<u>536.767</u>

Statement of income and expenses for the year 2016

	2016	<i>Budget</i> 2016	2015
	€	€	€
Income			
Member contributions	210.000	<i>210.000</i>	210.000
Associated member contributions	5.000	<i>5.000</i>	5.000
Company Forum contributions	44.274	<i>50.000</i>	48.333
Other contributions	12.290	<i>25.000</i>	40.309
Total income	<u>271.564</u>	<u><i>290.000</i></u>	<u>303.642</u>
Expenses			
Personnel expenses	121.031	<i>122.500</i>	115.529
Housing expenses	11.126	<i>12.000</i>	11.346
Activity expenses	120.361	<i>104.000</i>	196.272
Organizational expenses	48.617	<i>45.000</i>	50.778
Total operating expenses	<u>301.135</u>	<u><i>283.500</i></u>	<u>373.925</u>
Operating result	-29.571	<i>6.500</i>	-70.283
Interest income	1.686	<i>3.000</i>	3.085
Net result	<u>-27.885</u>	<u><i>9.500</i></u>	<u>-67.198</u>
Appropriation of result			
Continuity reserve	-	-	200.000
Reserve for 25th anniversary	30.000	-	-
Reserve for additional workshop costs	93.000	-	-
Other free reserves	-150.885	<i>9.500</i>	-267.198
	<u>-27.885</u>	<u><i>9.500</i></u>	<u>-67.198</u>

Cashflow statement for the year 2016

	2016		2015	
	€	€	€	€
Operating result		-29.571		-70.283
Adjustment for:				
Movement in provisions		-17.213		147.872
Changes in working capital:				
Other accounts receivable	13.673		14.637	
Current liabilities	<u>-1.616</u>		<u>-3.688</u>	
		<u>12.057</u>		<u>10.949</u>
Cash flow from operating activities		-34.727		88.538
Interest received		<u>1.686</u>		<u>3.085</u>
Cash movement		<u><u>-33.041</u></u>		<u><u>91.623</u></u>
Balance as at beginning of the financial year		518.654		427.031
Movement during the financial year		<u>-33.041</u>		<u>91.623</u>
Balance at the end to the financial year		<u><u>485.613</u></u>		<u><u>518.654</u></u>

Notes to the financial accounts

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 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 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 nominal value. Provisions deemed necessary for possible bad debt 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 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 (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 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**

	<u>31-12-2016</u>	<u>31-12-2015</u>
	€	€
Other receivables and accrued assets		
Other contributions	2.754	11.695
Company Forum contribution by Amicus Therapeutics	-	3.333
Bank interest	1.686	3.085
Member contributions	-	-
	<u>4.440</u>	<u>18.113</u>

2 Cash at banks

ING Top rente 68.44.14.880	354.358	471.272
ING RC 68.44.14.880	<u>131.255</u>	<u>47.382</u>
	<u>485.613</u>	<u>518.654</u>

3 Equity

Continuity reserve	200.000	200.000
Reserve for 25th anniversary	30.000	-
Reserve for additional workshop costs	93.000	-
Other free reserves	<u>6.858</u>	<u>157.743</u>
	<u>329.858</u>	<u>357.743</u>
	<u>2016</u>	<u>2015</u>
	€	€

Continuity reserve

Balance as at January 1	200.000	-
Appropriation of result	<u>-</u>	<u>200.000</u>
Balance as at December 31	<u>200.000</u>	<u>200.000</u>

The continuity reserve is established to be able to execute approved workshops, in case of a shortfall in raising the necessary funds. The height is put 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.

	<u>2016</u>	<u>2015</u>
	€	€
Reserve for 25th anniversary		
Balance as at January 1	-	-
Appropriation of result	<u>30.000</u>	<u>-</u>
Balance as at December 31	<u><u>30.000</u></u>	<u><u>-</u></u>

The purpose reserve of € 30.000 for the 25th anniversary is established by the Executive Committee (October 28, 2016) to pay for different events in 2017 and 2018 organised by the ENMC to celebrate the 25th anniversary of the ENMC:

- 1) An ENMC symposium at the ICNMD meeting in Vienna, 2018. This symposium is estimated to cost approximately € 3.000.
- 2) A Special ENMC Workshop on a patient-oriented topic in Milan, 2018. This workshop will cost approximately € 20.000.
- 3) A joined evening meeting in St-Malo, 2017, reflecting on 25 years ENMC with both Executive Committee and Research Committee members. Costs are estimated at € 7.000.

	<u>2016</u>	<u>2015</u>
	€	€
Reserve for additional workshop costs		
Balance as at January 1	-	-
Appropriation of result	<u>93.000</u>	<u>-</u>
Balance as at December 31	<u><u>93.000</u></u>	<u><u>-</u></u>

This workshop related reserve is created to approve 9 workshops per year instead of the budgeted 8 workshops, to allocate extra money per workshop to be able to change to a new hotel facility, to allocate extra money per workshop to cover additional costs for patients and to allocate extra money per workshop to cover costs for participants who have no funding. The purpose reserve of € 93.000 for additional workshop costs is established by the Executive Committee on October 28, 2016.

Other free reserves

Balance as at January 1	157.743	424.941
Appropriation of result (withdrawal)	<u>-150.885</u>	<u>-267.198</u>
Balance as at December 31	<u><u>6.858</u></u>	<u><u>157.743</u></u>

	<u>31-12-2016</u>	<u>31-12-2015</u>
	€	€
4 Workshop provisions		
Workshop 210	1.366	1.424
Workshop 211	4.762	4.762
Workshop 212	5.937	5.937
Workshop 213	200	-
Workshop 214	3.100	9.246
Workshop 215	2.627	9.503
Workshop 216	200	13.000
Workshop 217	3.800	13.000
Workshop 218	400	13.000
Workshop 219	2.235	13.000
Workshop 220	4.056	13.000
Workshop 221	2.261	13.000
Workshop 222	650	13.000
Workshop 223	350	13.000
Workshop 224	3.060	13.000
Workshop 225	4.655	-
Workshop 226	13.000	-
Workshop 227	13.000	-
Workshop 228	13.000	-
Workshop 229	13.000	-
Workshop 230	13.000	-
Workshop 231	13.000	-
Workshop 232	13.000	-
	<u>130.659</u>	<u>147.872</u>

Since the transitional year (2015) the expected costs per approved workshop are € 13.000. If a workshop is more expensive than € 13.000 the additional costs are included once they are known. The release for undeclared amounts for a workshop which is less expensive than € 13.000 will be recognized and deducted from the activity expenses when the workshop is (administratively) closed. Since the transitional year, none of the workshops could have been administratively closed yet. This explains that 2016 shows more costs for workshops than budgeted. In 2017 we expect to have the new system in balance, as the first workshops will be administratively closed.

	<u>2016</u>	<u>2015</u>
	€	€
Workshop 210		
Balance as at January 1	1.424	-
Provision	-	1.424
Expenses paid in the bookyear	-58	-
	<u>1.366</u>	<u>1.424</u>

	<u>2016</u>	<u>2015</u>
	€	€
Workshop 211		
Balance as at January 1	4.762	-
Provision	<u>-</u>	<u>4.762</u>
Balance as at December 31	<u><u>4.762</u></u>	<u><u>4.762</u></u>
Workshop 212		
Balance as at January 1	5.937	-
Provision	<u>-</u>	<u>5.937</u>
Balance as at December 31	<u><u>5.937</u></u>	<u><u>5.937</u></u>
Workshop 213		
Balance as at January 1	-	-
Provision	200	-
Expenses paid in the bookyear	-1.243	-
Additional provision	<u>1.243</u>	<u>-</u>
Balance as at December 31	<u><u>200</u></u>	<u><u>-</u></u>
Workshop 214		
Balance as at January 1	9.246	-
Provision	1.823	9.246
Expenses paid in the bookyear	<u>-7.969</u>	<u>-</u>
Balance as at December 31	<u><u>3.100</u></u>	<u><u>9.246</u></u>
Workshop 215		
Balance as at January 1	9.503	-
Provision	-	9.503
Expenses paid in the bookyear	<u>-6.876</u>	<u>-</u>
Balance as at December 31	<u><u>2.627</u></u>	<u><u>9.503</u></u>
Workshop 216		
Balance as at January 1	13.000	-
Provision	200	13.000
Expenses paid in the bookyear	-14.196	-
Additional provision	<u>1.196</u>	<u>-</u>
Balance as at December 31	<u><u>200</u></u>	<u><u>13.000</u></u>

	<u>2016</u>	<u>2015</u>
	€	€
Workshop 217		
Balance as at January 1	13.000	-
Provision	3.800	13.000
Expenses paid in the bookyear	-17.500	-
Additional provision	<u>4.500</u>	<u>-</u>
Balance as at December 31	<u><u>3.800</u></u>	<u><u>13.000</u></u>
Workshop 218		
Balance as at January 1	13.000	-
Provision	213	13.000
Expenses paid in the bookyear	<u>-12.813</u>	<u>-</u>
Balance as at December 31	<u><u>400</u></u>	<u><u>13.000</u></u>
Workshop 219		
Balance as at January 1	13.000	-
Provision	-	13.000
Expenses paid in the bookyear	<u>-10.765</u>	<u>-</u>
Balance as at December 31	<u><u>2.235</u></u>	<u><u>13.000</u></u>
Workshop 220		
Balance as at January 1	13.000	-
Provision	-	13.000
Expenses paid in the bookyear	<u>-8.944</u>	<u>-</u>
Balance as at December 31	<u><u>4.056</u></u>	<u><u>13.000</u></u>
Workshop 221		
Balance as at January 1	13.000	-
Provision	-	13.000
Expenses paid in the bookyear	<u>-10.739</u>	<u>-</u>
Balance as at December 31	<u><u>2.261</u></u>	<u><u>13.000</u></u>
Workshop 222		
Balance as at January 1	13.000	-
Provision	650	13.000
Expenses paid in the bookyear	-14.215	-
Additional provision	<u>1.215</u>	<u>-</u>
Balance as at December 31	<u><u>650</u></u>	<u><u>13.000</u></u>

	<u>2016</u>	<u>2015</u>
	€	€
Workshop 223		
Balance as at January 1	13.000	-
Provision	350	13.000
Expenses paid in the bookyear	-13.971	-
Additional provision	<u>971</u>	<u>-</u>
Balance as at December 31	<u><u>350</u></u>	<u><u>13.000</u></u>
Workshop 224		
Balance as at January 1	13.000	-
Provision	-	13.000
Expenses paid in the bookyear	<u>-9.940</u>	<u>-</u>
Balance as at December 31	<u><u>3.060</u></u>	<u><u>13.000</u></u>
Workshop 225		
Balance as at January 1	-	-
Provision	13.000	-
Expenses paid in the bookyear	<u>-8.345</u>	<u>-</u>
Balance as at December 31	<u><u>4.655</u></u>	<u><u>-</u></u>
Workshop 226		
Balance as at January 1	-	-
Provision	<u>13.000</u>	<u>-</u>
Balance as at December 31	<u><u>13.000</u></u>	<u><u>-</u></u>
Workshop 227		
Balance as at January 1	-	-
Provision	<u>13.000</u>	<u>-</u>
Balance as at December 31	<u><u>13.000</u></u>	<u><u>-</u></u>
Workshop 228		
Balance as at January 1	-	-
Provision	<u>13.000</u>	<u>-</u>
Balance as at December 31	<u><u>13.000</u></u>	<u><u>-</u></u>
Workshop 229		
Balance as at January 1	-	-
Provision	<u>13.000</u>	<u>-</u>
Balance as at December 31	<u><u>13.000</u></u>	<u><u>-</u></u>

	<u>2016</u>	<u>2015</u>
	€	€
Workshop 230		
Balance as at January 1	-	-
Provision	<u>13.000</u>	<u>-</u>
Balance as at December 31	<u><u>13.000</u></u>	<u><u>-</u></u>
Workshop 231		
Balance as at January 1	-	-
Provision	<u>13.000</u>	<u>-</u>
Balance as at December 31	<u><u>13.000</u></u>	<u><u>-</u></u>
Workshop 232		
Balance as at January 1	-	-
Provision	<u>13.000</u>	<u>-</u>
Balance as at December 31	<u><u>13.000</u></u>	<u><u>-</u></u>
Current liabilities		
	<u>31-12-2016</u>	<u>31-12-2015</u>
	€	€
5 Other payables		
Rental and service charges SN	11.000	11.000
Accounting and audit fees	6.913	7.550
Wage tax	7.141	6.461
Accrued holiday allowance	3.457	3.341
Joint meeting	-	1.800
Office costs	<u>1.025</u>	<u>1.000</u>
	<u><u>29.536</u></u>	<u><u>31.152</u></u>

Notes to the statements of activities

	<u>2016</u>	<i>Budget</i> <u>2016</u>	<u>2015</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	<u>-</u>	<u>210.000</u>	<u>-</u>
	<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>5.000</u>	<u>5.000</u>
8 Company Forum contributions			
Genzyme Europe B.V.	20.000	-	20.000
Santhera Pharmaceuticals	15.000	-	15.000
PTC Therapeutics	-	-	10.000
Amicus Therapeutics	3.313	-	3.333
Sanquin	1.500	-	-
Ionis	4.461	-	-
Total budget Company Forum	<u>-</u>	<u>50.000</u>	<u>-</u>
	<u>44.274</u>	<u>50.000</u>	<u>48.333</u>

	<u>2016</u>	<i>Budget</i> <u>2016</u>	<u>2015</u>
	€	€	€
9 Other contributions			
RYR-1 Foundation	-394	-	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
Joshua Frase Foundation	1.026	-	-
The Wyck Foundation	4.301	-	-
AveXis	506	-	-
Friends of FSH Research	4.097	-	-
FSH Society	1.023	-	-
FSHD Stichting	1.731	-	-
Other	-	-	2.566
Total budget other contributions	<u>-</u>	<u>25.000</u>	<u>-</u>
	<u>12.290</u>	<u>25.000</u>	<u>40.309</u>

The realized Other contributions are lower than budgeted because since 2016 most co-sponsors settled their contributions directly with the non-ENMC participants.

10 Personnel expenses

Salaries	80.817	-	77.969
Social charges	15.187	-	14.205
Pensions	12.080	-	11.509
Movement to accrual holiday allowance	5.982	-	5.587
Insurance sickleave current year	3.891	-	2.598
Total budget salaries	-	122.500	-
Other personnel expenses	<u>3.074</u>	<u>-</u>	<u>3.661</u>
	<u>121.031</u>	<u>122.500</u>	<u>115.529</u>

Average numbers of employees

During the year 2016 ENMC employed, converted to full-time equivalents, on average 1,3 employees with 2,0 employees in total (2015: idem).

11 Housing expenses

Office rental and services	<u>11.126</u>	<u>12.000</u>	<u>11.346</u>
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	<u>2016</u>	<i>Budget</i> <u>2016</u>	<u>2015</u>
	€	€	€
12 Activity expenses			
Workshop 207	-	-	485
Workshop 210	-	-	13.000
Workshop 211	-	-	13.000
Workshop 212	-	-	13.000
Workshop 213	1.443	-	15.400
Workshop 214	1.823	-	13.000
Workshop 215	-	-	13.000
Workshop 216	1.396	-	13.000
Workshop 217	8.300	-	13.000
Workshop 218	213	-	13.000
Workshop 219	-	-	13.000
Workshop 220	-	-	13.000
Workshop 221	-	-	13.000
Workshop 222	1.865	-	13.000
Workshop 223	1.321	-	13.000
Workshop 224	-	-	13.000
Workshop 225	13.000	13.000	-
Workshop 226	13.000	13.000	-
Workshop 227	13.000	13.000	-
Workshop 228	13.000	13.000	-
Workshop 229	13.000	13.000	-
Workshop 230	13.000	13.000	-
Workshop 231	13.000	13.000	-
Workshop 232	13.000	13.000	-
Company Forum costs	-	-	1.272
Non-declared amounts previous years	-	-	-2.885
	<u>120.361</u>	<u>104.000</u>	<u>196.272</u>

13 Organizational expenses

Research committee/ director	14.449	17.500	17.639
Audit costs and salary administration	12.816	8.000	7.950
Website	2.939	2.000	6.522
Executive Committee	2.539	5.500	5.743
Marketing	7.523	4.000	4.073
Congress expenses	4.994	3.000	3.021
Office costs - Baarn	831	5.000	2.987
Bank expenses	1.093	-	928
Travelling and hotel expenses	-	-	785
Insurance premium	712	-	586
Telephone expenses	721	-	544
	<u>48.617</u>	<u>45.000</u>	<u>50.778</u>

Baarn, April 24 , 2017
European Neuro Muscular Centre

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