

Financial accounts - December 31, 2017

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 December 31, 2017*After proposal profit appropriation*

		<u>31-12-2017</u>	<u>31-12-2016</u>
		€	€
ASSETS			
Current assets			
Other receivables	1	1.525	4.440
Cash at banks	2	<u>491.595</u>	<u>485.613</u>
		<u>493.120</u>	<u>490.053</u>
EQUITY AND LIABILITIES			
Equity	3	353.690	329.858
Provisions			
Workshop provisions	4	82.152	130.659
Current liabilities			
Other payables	5	<u>57.278</u>	<u>29.536</u>
		<u>493.120</u>	<u>490.053</u>

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Statement of income and expenses for the year 2017

	2017	<i>Budget</i> 2017	2016
	€	€	€
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	63.957	<i>65.000</i>	44.274
Other contributions	32.792	<i>31.500</i>	12.290
Total income	<u>311.749</u>	<u><i>311.500</i></u>	<u>271.564</u>
Expenses			
Personnel expenses	149.034	<i>149.837</i>	121.031
Housing expenses	11.997	<i>11.500</i>	11.126
Activity expenses	87.114	<i>155.000</i>	120.361
Organizational expenses	40.274	<i>43.300</i>	48.617
Total operating expenses	<u>288.419</u>	<u><i>359.637</i></u>	<u>301.135</u>
Operating result	23.330	<i>-48.137</i>	-29.571
Interest income	502	<i>1.600</i>	1.686
Net result	<u>23.832</u>	<u><i>-46.537</i></u>	<u>-27.885</u>
Appropriation of result			
Continuity reserve	-	-	-
Reserve for 25th anniversary	-8.009	<i>-20.000</i>	30.000
Reserve for additional workshop costs	-15.155	<i>-31.000</i>	93.000
Other free reserves	46.996	<i>4.463</i>	-150.885
	<u>23.832</u>	<u><i>-46.537</i></u>	<u>-27.885</u>

Cashflow statement for the year 2017

	2017		2016	
	€	€	€	€
Operating result		23.330		-29.571
Adjustment for:				
Movement in provisions		-48.507		-17.213
Changes in working capital:				
Other accounts receivable	2.915		13.673	
Current liabilities	<u>27.742</u>		<u>-1.616</u>	
		<u>30.657</u>		<u>12.057</u>
Cash flow from operating activities		5.480		-34.727
Interest received		<u>502</u>		<u>1.686</u>
Cash movement		<u><u>5.982</u></u>		<u><u>-33.041</u></u>
Balance as at beginning of the financial year		485.613		518.654
Movement during the financial year		<u>5.982</u>		<u>-33.041</u>
Balance at the end to the financial year		<u><u>491.595</u></u>		<u><u>485.613</u></u>

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 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 amortised cost price. 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 amortised cost price.

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>31-12-2017</u>	<u>31-12-2016</u>
	€	€
Other receivables and accrued assets		
Other contributions	1.023	2.754
Bank interest	<u>502</u>	<u>1.686</u>
	<u>1.525</u>	<u>4.440</u>

2 Cash at banks

ING Top rente 68.44.14.880	45.551	354.358
ING RC 68.44.14.880	<u>446.044</u>	<u>131.255</u>
	<u>491.595</u>	<u>485.613</u>

3 Equity

Continuity reserve	200.000	200.000
Reserve for 25th anniversary	21.991	30.000
Reserve for additional workshop costs	77.845	93.000
Other free reserves	<u>53.854</u>	<u>6.858</u>
	<u>353.690</u>	<u>329.858</u>

	<u>2017</u>	<u>2016</u>
	€	€
Continuity reserve		
Balance as at January 1	200.000	200.000
Appropriation of result	<u>-</u>	<u>-</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>2017</u>	<u>2016</u>
	€	€
Reserve for 25th anniversary		
Balance as at January 1	30.000	-
Appropriation of result: Expenses paid in the bookyear	-16.536	-
Appropriation of result: Co-sponsorship Audentes Therapeutics	8.527	-
Appropriation of result	<u>-</u>	<u>30.000</u>
Balance as at December 31	<u><u>21.991</u></u>	<u><u>30.000</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 (cumulative actual costs at 31-12-17: € 0).
- 2) A Special ENMC Workshop on a patient-oriented topic in Milan, 2018. This workshop will cost approximately € 20.000 (cumulative actual costs at 31-12-17: € 14.018 of which €8.527 will be covered by the co-sponsorship by Audentes Therapeutics, see page 18).
- 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 (cumulative actual costs at 31-12-17: € 2.518).

	<u>2017</u>	<u>2016</u>
	€	€
Reserve for additional workshop costs		
Balance as at January 1	93.000	-
Appropriation of result: Expenses paid in the bookyear	-5.155	-
Appropriation of result: Release in favor of provision workshops (5 workshops x € 2.000)	-10.000	-
Appropriation of result	<u>-</u>	<u>93.000</u>
Balance as at December 31	<u><u>77.845</u></u>	<u><u>93.000</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.

Release in favor of provision workshops

In 2017, five out of the possible nine workshops were approved. For these five workshops (233, 234, 236, 237 and 238) a total amount of € 10.000,- (5 x € 2.000,-) will be released from the "Reserve for additional workshop costs". Workshop 235 will be fully paid out of the "Reserve for the 25th Anniversary events".

	<u>2017</u>	<u>2016</u>
	€	€
Other free reserves		
Balance as at January 1	6.858	157.743
Appropriation of result	<u>46.996</u>	<u>-150.885</u>
Balance as at December 31	<u><u>53.854</u></u>	<u><u>6.858</u></u>

	<u>31-12-2017</u>	<u>31-12-2016</u>
	€	€
4 Workshop provisions		
Workshop 210	-	1.366
Workshop 211	-	4.762
Workshop 212	-	5.937
Workshop 213	-	200
Workshop 214	-	3.100
Workshop 215	-	2.627
Workshop 216	-	200
Workshop 217	-	3.800
Workshop 218	-	400
Workshop 219	-	2.235
Workshop 220	-	4.056
Workshop 221	-	2.261
Workshop 222	-	650
Workshop 223	-	350
Workshop 224	-	3.060
Workshop 225	-	4.655
Workshop 226	3.794	13.000
Workshop 227	2.488	13.000
Workshop 228	3.760	13.000
Workshop 229	3.841	13.000
Workshop 230	3.250	13.000
Workshop 231	3.000	13.000
Workshop 232	1.254	13.000
Workshop 233	4.772	-
Workshop 234	10.993	-
Workshop 236	15.000	-
Workshop 237	15.000	-
Workshop 238	15.000	-
	<u>82.152</u>	<u>130.659</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 budgeted will be recognized and deducted from the activity expenses when the workshop is (administratively) closed.

As approved at the meeting of the Executive Committee on October 28, 2016, also an extra provision of € 2.000 per workshop from now on is made to cover costs of additional patient facilities (€ 500), participants from Eastern European countries (€ 500), and new hotel facilities (€ 1.000). This explains the change in workshop provision from € 13.000 to € 15.000, starting with the first workshops (233 and 234) approved at the meeting of April 12, 2017 (see page 16 and 17).

	<u>2017</u>	<u>2016</u>
	€	€
Workshop 210 (administratively closed)		
Balance as at January 1	1.366	1.424
Provision	-	-
Expenses paid in the bookyear	-	-58
Not declared	<u>-1.366</u>	<u>-</u>
Balance as at December 31	<u>-</u>	<u>1.366</u>
Workshop 211 (administratively closed)		
Balance as at January 1	4.762	4.762
Not declared	<u>-4.762</u>	<u>-</u>
Balance as at December 31	<u>-</u>	<u>4.762</u>
Workshop 212 (administratively closed)		
Balance as at January 1	5.937	5.937
Not declared	<u>-5.937</u>	<u>-</u>
Balance as at December 31	<u>-</u>	<u>5.937</u>
Workshop 213 (administratively closed)		
Balance as at January 1	200	-
Provision	-	200
Expenses paid in the bookyear	-	-1.243
Additional provision	-	1.243
Not declared	<u>-200</u>	<u>-</u>
Balance as at December 31	<u>-</u>	<u>200</u>
Workshop 214 (administratively closed)		
Balance as at January 1	3.100	9.246
Provision	-	1.823
Expenses paid in the bookyear	-	-7.969
Not declared	<u>-3.100</u>	<u>-</u>
Balance as at December 31	<u>-</u>	<u>3.100</u>
Workshop 215 (administratively closed)		
Balance as at January 1	2.627	9.503
Expenses paid in the bookyear	-	-6.876
Not declared	<u>-2.627</u>	<u>-</u>
Balance as at December 31	<u>-</u>	<u>2.627</u>

	<u>2017</u>	<u>2016</u>
	€	€
Workshop 216 (administratively closed)		
Balance as at January 1	200	13.000
Provision	-	200
Expenses paid in the bookyear	-	-14.196
Additional provision	-	1.196
Not declared	<u>-200</u>	<u>-</u>
Balance as at December 31	<u>-</u>	<u>200</u>
Workshop 217 (administratively closed)		
Balance as at January 1	3.800	13.000
Provision	-	3.800
Expenses paid in the bookyear	-300	-17.500
Additional provision	-	4.500
Not declared	<u>-3.500</u>	<u>-</u>
Balance as at December 31	<u>-</u>	<u>3.800</u>
Workshop 218 (administratively closed)		
Balance as at January 1	400	13.000
Provision	-	213
Expenses paid in the bookyear	-194	-12.813
Not declared	<u>-206</u>	<u>-</u>
Balance as at December 31	<u>-</u>	<u>400</u>
Workshop 219 (administratively closed)		
Balance as at January 1	2.235	13.000
Expenses paid in the bookyear	-	-10.765
Not declared	<u>-2.235</u>	<u>-</u>
Balance as at December 31	<u>-</u>	<u>2.235</u>
Workshop 220 (administratively closed)		
Balance as at January 1	4.056	13.000
Expenses paid in the bookyear	-439	-8.944
Not declared	<u>-3.617</u>	<u>-</u>
Balance as at December 31	<u>-</u>	<u>4.056</u>
Workshop 221 (administratively closed)		
Balance as at January 1	2.261	13.000
Expenses paid in the bookyear	-394	-10.739
Not declared	<u>-1.867</u>	<u>-</u>
Balance as at December 31	<u>-</u>	<u>2.261</u>

	<u>2017</u>	<u>2016</u>
	€	€
Workshop 222 (administratively closed)		
Balance as at January 1	650	13.000
Provision	-	650
Expenses paid in the bookyear	-216	-14.215
Additional provision	-	1.215
Not declared	-434	-
	<u>-</u>	<u>-</u>
Balance as at December 31	<u>-</u>	<u>650</u>
Workshop 223 (administratively closed)		
Balance as at January 1	350	13.000
Provision	-	350
Expenses paid in the bookyear	-26	-13.971
Additional provision	-	971
Not declared	-324	-
	<u>-</u>	<u>-</u>
Balance as at December 31	<u>-</u>	<u>350</u>
Workshop 224 (administratively closed)		
Balance as at January 1	3.060	13.000
Expenses paid in the bookyear	-	-9.940
Not declared	-3.060	-
	<u>-</u>	<u>-</u>
Balance as at December 31	<u>-</u>	<u>3.060</u>
Workshop 225		
Balance as at January 1	4.655	-
Provision	-	13.000
Expenses paid in the bookyear	-6.165	-8.345
Additional provision	1.510	-
	<u>-</u>	<u>-</u>
Balance as at December 31	<u>-</u>	<u>4.655</u>
Workshop 226		
Balance as at January 1	13.000	-
Provision	-	13.000
Expenses paid in the bookyear	-9.206	-
	<u>-</u>	<u>-</u>
Balance as at December 31	<u>3.794</u>	<u>13.000</u>
Workshop 227		
Balance as at January 1	13.000	-
Provision	-	13.000
Expenses paid in the bookyear	-10.512	-
	<u>-</u>	<u>-</u>
Balance as at December 31	<u>2.488</u>	<u>13.000</u>

	<u>2017</u>	<u>2016</u>
	€	€
Workshop 228		
Balance as at January 1	13.000	-
Provision	-	13.000
Expenses paid in the bookyear	<u>-9.240</u>	<u>-</u>
Balance as at December 31	<u><u>3.760</u></u>	<u><u>13.000</u></u>
Workshop 229		
Balance as at January 1	13.000	-
Provision	-	13.000
Expenses paid in the bookyear	<u>-9.159</u>	<u>-</u>
Balance as at December 31	<u><u>3.841</u></u>	<u><u>13.000</u></u>
Workshop 230		
Balance as at January 1	13.000	-
Provision	-	13.000
Expenses paid in the bookyear	-12.509	-
Additional provision	<u>2.759</u>	<u>-</u>
Balance as at December 31	<u><u>3.250</u></u>	<u><u>13.000</u></u>
Workshop 231		
Balance as at January 1	13.000	-
Provision	-	13.000
Expenses paid in the bookyear	-13.711	-
Additional provision	<u>3.711</u>	<u>-</u>
Balance as at December 31	<u><u>3.000</u></u>	<u><u>13.000</u></u>
Workshop 232		
Balance as at January 1	13.000	-
Provision	-	13.000
Expenses paid in the bookyear	<u>-11.746</u>	<u>-</u>
Balance as at December 31	<u><u>1.254</u></u>	<u><u>13.000</u></u>
Workshop 233		
Balance as at January 1	-	-
Provision	15.000	-
Expenses paid in the bookyear	<u>-10.228</u>	<u>-</u>
Balance as at December 31	<u><u>4.772</u></u>	<u><u>-</u></u>

	<u>2017</u>	<u>2016</u>
	€	€
Workshop 234		
Balance as at January 1	-	-
Provision	15.000	-
Expenses paid in the bookyear	<u>-4.007</u>	<u>-</u>
Balance as at December 31	<u><u>10.993</u></u>	<u><u>-</u></u>
Workshop 236		
Balance as at January 1	-	-
Provision	<u>15.000</u>	<u>-</u>
Balance as at December 31	<u><u>15.000</u></u>	<u><u>-</u></u>
Workshop 237		
Balance as at January 1	-	-
Provision	<u>15.000</u>	<u>-</u>
Balance as at December 31	<u><u>15.000</u></u>	<u><u>-</u></u>
Workshop 238		
Balance as at January 1	-	-
Provision	<u>15.000</u>	<u>-</u>
Balance as at December 31	<u><u>15.000</u></u>	<u><u>-</u></u>
Current liabilities		
	<u>31-12-2017</u>	<u>31-12-2016</u>
	€	€
5 Other payables		
Payable for literature analysis	15.000	-
Rental and service charges SN	11.297	11.000
Creditors	8.842	-
Accounting and audit fees	6.050	6.913
Wage tax	9.358	7.141
Pension premium	671	-
Accrued holiday allowance	4.233	3.457
Office costs	949	1.025
Payables to organisers of workshop administratively closed	<u>878</u>	<u>-</u>
	<u><u>57.278</u></u>	<u><u>29.536</u></u>

Notes to the statements of activities

	<u>2017</u>	<i>Budget</i> <u>2017</u>	<u>2016</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			
Sanofi Genzyme	20.000	-	20.000
Santhera Pharmaceuticals	15.000	-	15.000
CSL Behring	19.985	-	-
Amicus Therapeutics	3.333	-	3.313
Sanquin	1.500	-	1.500
Ionis Pharmaceuticals	4.139	-	4.461
Total budget Company Forum	<u>-</u>	<u>65.000</u>	<u>-</u>
	<u>63.957</u>	<u>65.000</u>	<u>44.274</u>

	<u>2017</u>	<i>Budget</i> <u>2017</u>	<u>2016</u>
	€	€	€
9 Other contributions			
RYR-1 Foundation	-	-	-394
Grifols (workshop 230)	10.000	-	-
Grifols (workshop 231)	7.000	-	-
Muscular Dystrophy Association	4.449	-	-
Parent Project Muscular Dystrophy	2.389	-	-
Audentes Therapeutics (workshop 235)	8.527	-	-
Alexander's Way Research Fund Inc	427	-	-
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
Total budget other contributions	<u>-</u>	<u>31.500</u>	<u>-</u>
	<u><u>32.792</u></u>	<u><u>31.500</u></u>	<u><u>12.290</u></u>

10 Personnel expenses

Salaries	99.978	-	80.817
Social charges	17.740	-	15.187
Pensions	16.764	-	12.080
Movement to accrual holiday allowance	7.401	-	5.982
Insurance sickleave current year	3.283	-	3.891
Total budget salaries	-	<i>146.337</i>	-
Other personnel expenses	<u>3.868</u>	<u>3.500</u>	<u>3.074</u>
	<u><u>149.034</u></u>	<u><u>149.837</u></u>	<u><u>121.031</u></u>

Average numbers of employees

During the year 2017 ENMC employed, converted to full-time equivalents, on average 1,6 employees (2016: average 1,3).

11 Housing expenses

Office rental and services	<u>11.997</u>	<u>11.500</u>	<u>11.126</u>
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	<u>2017</u>	<i>Budget</i> <u>2017</u>	<u>2016</u>
	€	€	€
12 Activity expenses			
Workshop 213	-	-	1.443
Workshop 214	-	-	1.823
Workshop 216	-	-	1.396
Workshop 217	-	-	8.300
Workshop 218	-	-	213
Workshop 222	-	-	1.865
Workshop 223	-	-	1.321
Workshop 225	1.510	-	13.000
Workshop 226	-	-	13.000
Workshop 227	-	-	13.000
Workshop 228	-	-	13.000
Workshop 229	-	-	13.000
Workshop 230	2.759	-	13.000
Workshop 231	3.711	-	13.000
Workshop 232	-	-	13.000
Workshop 233	15.000	15.000	-
Workshop 234	15.000	15.000	-
Workshop 235	14.018	20.000	-
Workshop 236	15.000	15.000	-
Workshop 237	15.000	15.000	-
Workshop 238	15.000	15.000	-
Unused budget for four workshops	-	60.000	-
Literature analysis	15.000	-	-
Expenses joint evening meeting (St-Malo)	2.518	-	-
Expenses for additional workshop costs	5.155	-	-
Additional amounts previous workshops	878	-	-
Non-declared amounts previous years	-33.435	-	-
	<u>87.114</u>	<u>155.000</u>	<u>120.361</u>

One of the gaps identified from the impact analysis performed in 2017, was the ENMC literature analysis. At the Executive Committee (EC) meeting of 8 November 2017, it was suggested and approved by all EC members that this literature analysis is needed and should be performed by a professional bibliometric center. After a competitive quote evaluation, the Centre for Science and Technology studies (CWTS, Leiden, The Netherlands) was chosen and the ENMC confirmed their assignment for this project on December 28, 2017. Since only five out of the possible nine workshops were approved in 2017, this literature analysis estimated at € 15.000,- will be paid out of the Activity Expenses of 2017.

	<u>2017</u>	<i>Budget</i> <u>2017</u>	<u>2016</u>
	€	€	€
13 Organizational expenses			
Research committee/ director	13.320	17.800	14.449
Audit costs and salary administration	7.489	8.000	12.816
Website and IT	1.345	2.500	2.939
Executive Committee	2.563	3.000	2.539
Marketing	2.662	2.000	7.523
Congress expenses	7.398	5.000	4.994
Office costs - Baarn	2.257	2.500	831
Bank expenses	1.039	-	1.093
Travelling expenses	510	-	-
Insurance premium	722	-	712
Telephone expenses	969	-	721
Other	-	2.500	-
	<u>40.274</u>	<u>43.300</u>	<u>48.617</u>

Baarn, May 24, 2018
European Neuro Muscular Centre

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