

## Patients' and consumers' organisation funding sources

**NAME OF ORGANISATION: United Parent Projects MD**

**YEAR: 2017**

Industry <sup>1</sup> related income <sup>2</sup>		
Name of company/ funder	Amount of income	% of overall organisation's income
Sarepta	600	1,08%
Santhera	500	0,90%
PTC-therapeutics	600	1,08%
Catabis Pharmaceuticals	500	0,90%
Bristol Meyers Squibb	500	0,90%
Italfarmaco	500	0,90%

<sup>1</sup> Industry is defined as commercial manufacturers of healthcare products and services, including distributors and wholesalers, etc.

<sup>2</sup> This should reflect the overall funding received from industry, including, e.g. projects, conferences, etc.

Pfizer	964	1,74%
Capricor Therapeutics	500	0,90%
Reveragen Biopharma	500	0,90%
Solid Biosciences	1100	1,99%
Summit Therapeutics PLC	500	0,90%
<b>Subtotal:</b>	<b>6764</b>	<b>12,22%</b>

### Non-industry related income

Source of funding <sup>3</sup>	Amount of income	% of overall organisation's income
Parent Project	1000	1,81%
MDA Ellas	392	0,71%
Stiftelsen	264	0,48%
Muscular Dystrophy foundation CA	50	0,09%

<sup>3</sup> E.g. membership fees, donations.

Parent Project Romania	50	0,09%
DUCHENNE PARENT PROJECT ONLUS	50	0,09%
LITTLE STEPS	50	0,09%
DUCHENNE IRELAND LIMITED	102	0,18%
DUCHENNE CZECH	914	1,65%
DUCHENNE UK	1000	1,81%
SAVE OUR SONS AUSTRALIA	50	0,09%
PARENT PROJECT SRI LANKA	50	0,09%
MDA HELLAS	50	0,09%
PARENT PROJECT POLAND	50	0,09%
ADMO AC	50	0,09%
LAND FOR HOPE LEBANON	50	0,09%
DUCHENNE RUSSIA FAMILY	50	0,09%

DUCHENNE ARGENTINA	50	0,09%
DMD SRBIJA	50	0,09%
MDA CYPRUS	500	0,90%
DMD KENYA	50	0,09%
DUCHENNE BRAZIL	50	0,09%
MDSA SOUTH AFRICA	50	0,09%
PPMD USA	1000	1,81%
DUCHENNE PARENT PROJECT	1000	1,81%
BOARD ACTION DUCHENNE	1000	1,81%
DUCHENNE SPAIN	1000	1,81%
NEMA VZW BELGIUM	50	0,09%
DUCHENNE RESEARCH FUND	50	0,09%
JOIN OUR BOYS FOUNDATION	50	0,09%

PROGENA FOUNDATION	500	0,90%
Duchenne Balloon	12946	23,38%
Newcastle University Co-Ordina Vision DMD	26033	47,02%
<b>Subtotal:</b>	<b>48602</b>	<b>87,78%</b>
<b>TOTAL<sup>4</sup>:</b>	<b>55366</b>	<b>100%</b>
<b>Correction old years 2015/2016. See annual report 2017 to see more information.</b>	<b>-26350</b>	<b>XXX</b>
<b>Total compared to the annual report 2017</b>	<b>29015,91</b>	<b>XXX</b>

To see our criteria, look at: <https://worldduchenne.org/membership/criteria/>

Information required to be included on organisation's website	Please include links below:
<ul style="list-style-type: none"> <li>Funding sources:</li> </ul>	<a href="https://worldduchenne.org/aboutus/organization/">https://worldduchenne.org/aboutus/organization/</a>
<ul style="list-style-type: none"> <li>Overall proportion of industry and non-industry:</li> </ul>	87,78% non industry – 12,22 industry
<ul style="list-style-type: none"> <li>Percentage of the highest contribution from a single company:</li> </ul>	1,99%

<sup>4</sup> In case the total figures in this table do not match those in the financial statement, please provide justification (attached here or as an email).

### Comments/explanatory notes:

UPPMD does not receive sponsoring from companies. The only income from companies is the registration fee for roundtable meetings which is € 500 per company for 3 participants per meeting. Any additional participants pay € 100. These meetings take place twice a year (Rome and Birmingham/London). Any additional participants pay € 100. The fee for representatives of our member organisations for these roundtable meetings is included in their membership fee.

When completing the form you may refer to the guidance document here (in particular point 4, pages 8-9):

[http://www.ema.europa.eu/docs/en\\_GB/document\\_library/Regulatory\\_and\\_procedural\\_guideline/2015/05/WC500187018.pdf](http://www.ema.europa.eu/docs/en_GB/document_library/Regulatory_and_procedural_guideline/2015/05/WC500187018.pdf)