

## Patients' and consumers' organisation funding sources

**NAME OF ORGANISATION: United Parent Projects MD**  
**YEAR: 2018**

Industry <sup>1</sup> related income <sup>2</sup>		
Name of company/ funder	Amount of income	% of overall organisation's income
SANTHERA PHARMACEUTICALS	500	0,20%
PTC THERAPEUTICS	500	0,20%
CATABASIS PHARMACEUTICALS	491	0,20%
WAVE LIFE SCIENCES USA	500	0,20%
ITALFARMACO S.P.A.	500	0,20%
SUMMIT THERAPEUTICS PLC	500	0,20%
CORRECTION OLD YEARS	-608	-0,25%
<b>Subtotal:</b>	<b>2.383</b>	<b>0,98%</b>

<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.

## Non-industry related income

Source of funding <sup>3</sup>	Amount of income	% of overall organisation's income
PROGENA FOUNDATION	50	0,02%
DUCHENNE PARENT PROJECT ONLUS	1950	0,80%
AFM TELETHON	1000	0,41%
DUCHENNE IRELAND	50	0,02%
DUCHENNE UK	1000	0,41%
SAVE OUR SONS AUSTRALIA	1000	0,41%
PARENT PROJECT SRI LANKA	50	0,02%
MDA HELLAS	1000	0,41%
FOUNDATION SWEDEN	251	0,10%
ADMO A.C.	50	0,02%

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

DUCHENNE ARGENTINA	-50	-0,02%
DMD SRBIJA	50	0,02%
DUCHENNE BRAZIL	50	0,02%
PPMD USA	1000	0,41%
DUCHENNE PARENT PROJECT NETHERLANDS	1526	0,62%
ACTION DUCHENNE	1000	0,41%
DUCHENNE SPAIN	1000	0,41%
NEMA VZW BELGIUM	1050	0,43%
DUCHENNE RESEARCH FUND	1000	0,41%
ASS FRANCAISE CONTRE LES MYOPATHIES	1000	0,41%
CORRECTION OLD YEAR(S)	-8800	-3,60%
DONATIONS FACEBOOK	1234	0,51%
SHARE 4 RARE	156375	64,02%

NEWCASTLE UNIVERSITY CO-ORDINA VISION DMD	79044	32,36%
<b>Subtotal:</b>	<b>241881</b>	<b>99,02%</b>
<b>TOTAL<sup>4</sup>:</b>	<b>244264</b>	<b>100%</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>	99,02% non industry – 0,98% industry
<ul style="list-style-type: none"> <li>Percentage of the highest contribution from a single company(industry):</li> </ul>	0,20%

### Comments/explanatory notes:

UPPMD does not receive sponsoring from companies. The only income from companies is the registration fee for roundtable meetings which was € 500 per company for 3 participants per meeting. 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)

<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).