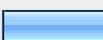
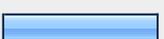
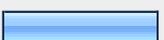
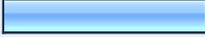


# ECHDO survey 1

1. Do you agree with: two levels of membership, according to activity: 1. Active and 2. Passive or associate (Active attends, participates and votes; Passive attends and participates but doesn't vote)?			
		Response Percent	Response Count
Yes		76.5%	13
No		17.6%	3
I think there should be another membership structure; explanation:		5.9%	1
<b>answered question</b>			<b>17</b>
<b>skipped question</b>			<b>1</b>

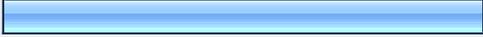
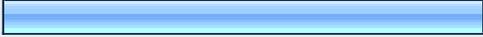
2. Regarding Membership Voting (Organisational, not Individual):			
		Response Percent	Response Count
One country, one vote		22.2%	4
One national (umbrella) organisation, one vote		11.1%	2
Many members per country, one (consensus) vote in total		16.7%	3
(Unlimited) members per country, votes for each member (according to activity of each member described above – active or passive)		16.7%	3
Votes per country according to size of patient population (ie, 1 for Portugal, 4 for Spain...) decided by consensus within each country		5.6%	1
<b>10 votes per country, to be distributed within country</b>		<b>33.3%</b>	<b>6</b>
Votes per budget of member organisation (the larger the budget, the more votes allotted)		0.0%	0
Please describe any relevant experience/story:			4
<b>answered question</b>			<b>18</b>

## 3. Should Board of Directors/Executive Committee membership be limited to one per country?

		Response Percent	Response Count
Yes		77.8%	14
No		22.2%	4
Your relevant story:			2
<b>answered question</b>			<b>18</b>
<b>skipped question</b>			<b>0</b>

## 4. Do you agree that Board of Directors/Executive Committee members need to be insured (against legal actions to the European organization)?

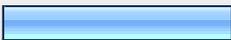
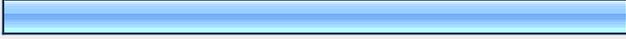
		Response Percent	Response Count
Yes		94.1%	16
No		5.9%	1
Your relevant experience:			6
<b>answered question</b>			<b>17</b>
<b>skipped question</b>			<b>1</b>

5. Membership fees				
			Response Percent	Response Count
Flat fee per member (i.e., 400 euros / annum for everyone)			11.8%	2
<b>Sliding scale according to Member's budget, or waiver/reduction system</b>			52.9%	9
<b>Active members – higher fee; passive members – lower/no fee</b>			52.9%	9
No fee for members			0.0%	0
Relevant experience:				4
<b>answered question</b>				<b>17</b>
<b>skipped question</b>				<b>1</b>

6. Important factors in deciding where the central office should be						
	Unimportant	I can take it or leave it	Very important	Vital	Rating Average	Response Count
Ability to produce work (strong local organization)	11.1% (2)	5.6% (1)	<b>50.0% (9)</b>	33.3% (6)	3.06	18
Ability to access Brussels (EU)	11.1% (2)	<b>33.3% (6)</b>	22.2% (4)	<b>33.3% (6)</b>	2.78	18
Costs involved	5.6% (1)	5.6% (1)	<b>72.2% (13)</b>	16.7% (3)	3.00	18
Legal translations (for accounts, etc)	11.1% (2)	22.2% (4)	<b>55.6% (10)</b>	11.1% (2)	2.67	18
Other important factor (please specify):						7
<b>answered question</b>						<b>18</b>
<b>skipped question</b>						<b>0</b>

7. Is the European General Assembly every year (to vote on annual budgets and approve the previous year's spending) or is it every other year?			Response Percent	Response Count
Every Year (Annually)			72.2%	13
Every other year			27.8%	5
		<i>answered question</i>		18
		<i>skipped question</i>		0

8. How much does it cost in your country to set up a not-for-profit organisation? (If there is no cost, please let us know that.)			Response Count
			17
		<i>answered question</i>	17
		<i>skipped question</i>	1

9. If the European organisation were set up in your country, could a foreign foundation (or company) contribute money legally using a tax ID number from your country?			Response Percent	Response Count
Yes			25.0%	4
No			6.3%	1
Unsure			68.8%	11
		<i>answered question</i>		16
		<i>skipped question</i>		2

**10. In your country, is there an important legal difference between an association, a federation, a network, and a foundation?  
Might one of them be better able to carry out European-wide work?**

		Response Percent	Response Count
Yes		47.1%	8
No		17.6%	3
Unsure		35.3%	6
Relevant story:			6
<b><i>answered question</i></b>			<b>17</b>
<b><i>skipped question</i></b>			<b>1</b>