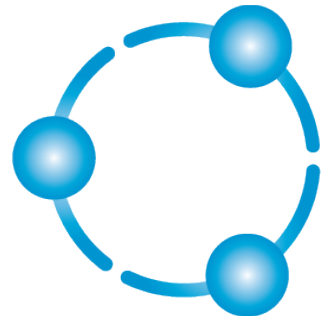


# Mitochondrial Disease Awareness Study

Prepared for: Australian Mitochondrial Disease Foundation  
May 2011





# 1. Methodology

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## 2. Main Findings

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# Main Findings

- ▶ Overall, one in three (32%) Australians are aware of mitochondrial disease when prompted with the name. This is the same level of awareness as in May 2010 (33%).
- ▶ Similarly, the levels of awareness of Lupus and motor neurone disease are very similar to 2010 levels. In 2011 three quarters of the population of Australians are aware of Lupus (79%, compared to 77% in 2010) and 81% of Australians are aware of motor neurone disease (compared to 82% in 2010).
- ▶ Awareness of mitochondrial disease is spread across the community by age and gender, although awareness is somewhat lower among those with educational qualifications below Year 12 (20%) or low income households (26%).
- ▶ Among those who say that they are aware of mitochondrial disease, four in ten (44%, compared to 42% in 2010) are able to show knowledge and understanding of the disease by saying that it is 'a serious disease that robs the body cells of energy and can affect various organs'. One in five (22%, compared to 25% in 2010) attribute it to being an autoimmune disease while 9% (8% in 2010) say that it is an inflammatory disease that affects the cartilage and joints. One in ten (9%, compared to 4% in 2010) say that it is an infectious disease spread by insects that leaves a person tired and fatigued (13% of Queenslanders and 16% of South Australians say this).



## Main Findings .... *continued*

- ▶ The youngest group (16-24 years) have the highest level of understanding of mitochondrial disease (59%) and the oldest group has the lowest level of understanding (35% among those aged 50 years and over), indicating that there is an age effect in the understanding of mitochondrial disease. Those with schooling at Year 12 or above have greater understanding than those with below Year 12 schooling (46% compared to 37%) suggesting that the education system is having some impact on the level of understanding of mitochondrial disease.
- ▶ The overall level of understanding of mitochondrial disease among all Australians aged 16 years and over is 14%. This is the same level of understanding as found in May 2010 indicating that the level of understanding has been maintained, but has not grown significantly at this time.



# 3. Questionnaire

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**SECTION C: ASK ALL PEOPLE AGED 16 YEARS AND OVER**

C1. Now some questions about diseases. Which of these diseases have you heard about before today, if any?

**READ OUT AND ROTATE 1-4**

	<u>MR</u>
Alheimers disease .....	1
Lupus .....	2
Mitochondrial disease.....	3
Motor neurone disease.....	4
None/ Don't know.....	5

**ASK IF AWARE OF MITOCHONDRIAL DISEASE IE CODE 3 IN C1 OTHERS GO TO NEXT SECTION**

C2. Which one of the following statements, if any, best describes mitochondrial disease?

**READ OUT AND ROTATE 1-4**

	<u>SR</u>
A serious genetic disease that robs the body cells of energy and can affect various organs..	1
An autoimmune disease that primarily affects the valves of the heart.....	2
An inflammatory disease that affects the cartilage and joints, impairing movement .....	3
An infectious disease spread by insects that leaves a person tired and fatigued.....	4
None/ Don't know .....	5



## 4. Detailed Tabular Findings

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# Tables

▶ **The tables of findings are set out such that they include the following details:**

**1 BASE: Weight Sample (000's):**

The number of completed interviews has been weighted to reflect the latest ABS population estimates. These estimates are shown in thousands (000's). The percentages in the table are based on these weighted figures.

**2 WEIGHTS:**

This indicates that in order to reflect the latest ABS population estimates the data has been weighted by age, gender and area.

**3 FILTERS (Where applicable):**

If the table is based on a subset of respondents then this will be titled as a Filter and accompanied by a description of the sample upon which the table is based.

**4 RESPONDENTS:**

These figures show the actual sample size, indicating the total number of respondents who were asked the relevant question.



# Tables ... continued

▶ Each question has been analysed by a series of demographic variables as follows:

→ **SEX:**

- Male
- Female

→ **AGE:**

- 16-24 years
- 25-34 years
- 35-49 years
- 50+ years

→ **MARITAL STATUS:**

- Married (married/de facto/living together)
- Not married (never married/separated/divorced/widowed)

→ **MAIN GROCERY BUYER:**

- Yes/Shared
- No



# Tables ... continued

## → CHILDREN AT HOME:

- Children under 18 living in the household
- No children under 18 living in the household

## → WORK STATUS:

- Working full-time
- Working part-time
- Not working

## → SOCIO-ECONOMIC STATUS:

- *Occupation of the main income earner of the household:*
  - White collar (professional/senior management, upper white collar, lower white collar)
  - Blue collar (upper blue collar, lower blue collar)

## → LOCATION:

- NSW / ACT
- Victoria / Tasmania
- Queensland
- South Australia
- Western Australia

## → CAPITAL CITY:

- Sydney, Melbourne, Brisbane, Adelaide or Perth
- Rest of Australia



# Tables ... continued

- **HOUSEHOLD INCOME:**
  - Under \$40,000
  - \$40,000 - \$69,999
  - \$70,000 plus
  
- **HIGHEST LEVEL OF SCHOOLING:**
  - Below Year 12
  - Year 12 and above

GALAXY RESEARCH  
TABLE 1 Standard Banner 1 \*BY\* C1 Diseases - Aided Awareness  
BASE: WGHT SAMPLE (000s)  
WEIGHTS: Age/Sex/Area

	Total	Sex		Age				Marital Status		Grocery Buyer		Children		Work Status			S.E.S.	
		Male	Female	16-24	25-34	35-49	50+	Marr-ied	Not Marr-ied	Yes /Shared	No	Yes	No	Full Time	Part Time	Not Working	White	Blue
RESPONDENTS	1100	550	550	158	116	379	447	671	429	739	361	438	662	473	236	391	636	464
WGHT SAMPLE (000s)	17585	8580	9005	2723	2862	5004	6996	10572	7013	11727	5858	7006	10579	7449	3713	6423	10122	7463
	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%
C1 Diseases - Aided Awareness																		
Alzheimers disease	16932 96%	8153 95%	8779 97%	2569 94%	2637 92%	4878 97%	6848 98%	10265 97%	6667 95%	11436 98%	5496 94%	6751 96%	10181 96%	7112 95%	3600 97%	6220 97%	9787 97%	7145 96%
Lupus	13829 79%	6089 71%	7740 86%	1576 58%	2174 76%	4339 87%	5740 82%	8927 84%	4902 70%	9834 84%	3996 68%	5373 77%	8456 80%	6127 82%	2891 78%	4811 75%	8160 81%	5669 76%
Mitochondrial disease	5705 32%	3031 35%	2674 30%	885 32%	845 30%	1936 39%	2040 29%	3281 31%	2424 35%	3964 34%	1741 30%	2252 32%	3453 33%	2666 36%	1393 38%	1646 26%	3775 37%	1930 26%
Motor neurone disease	14199 81%	6641 77%	7558 84%	1438 53%	1984 69%	4450 89%	6327 90%	9150 87%	5049 72%	10045 86%	4155 71%	5380 77%	8820 83%	6022 81%	2973 80%	5204 81%	8382 83%	5817 78%
None/ Don't know	471 3%	344 4%	127 1%	114 4%	194 7%	47 1%	117 2%	247 2%	224 3%	162 1%	310 5%	189 3%	283 3%	205 3%	89 2%	178 3%	238 2%	233 3%
TOTALS	51137 291%	24258 283%	26879 298%	6582 242%	7834 274%	15650 313%	21071 301%	31870 301%	19266 275%	35440 302%	15697 268%	19944 285%	31193 295%	22132 297%	10945 295%	18060 281%	30343 300%	20794 279%

GALAXY RESEARCH

TABLE 2

Standard Banner 2 \*BY\* C1 Diseases - Aided Awareness

BASE: WGHT SAMPLE (000s)

WEIGHTS: Age/Sex/Area

	Total	State				Capital City		Household Income			Schooling		
		NSW	Vic/Tas	Qld	SA	WA	Yes	No	< \$40K	\$40K-\$69K	\$70K+	Below Year 12	Year 12
RESPONDENTS	1100	330	310	200	130	130	700	400	289	231	422	324	776
WGHT SAMPLE (000s)	17585	6147	4869	3450	1378	1741	10827	6758	4623	3659	6671	5082	12503
	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%
C1 Diseases - Aided Awareness													
Alzheimers disease	16932	5942	4624	3326	1367	1673	10385	6546	4496	3483	6452	4904	12028
	96%	97%	95%	96%	99%	96%	96%	97%	97%	95%	97%	96%	96%
Lupus	13829	4960	3787	2738	1009	1336	8449	5380	3541	2941	5646	4000	9830
	79%	81%	78%	79%	73%	77%	78%	80%	77%	80%	85%	79%	79%
Mitochondrial disease	5705	2054	1496	1054	466	635	3706	1999	1185	1290	2493	1016	4689
	32%	33%	31%	31%	34%	36%	34%	30%	26%	35%	37%	20%	38%
Motor neurone disease	14199	4995	3920	2794	1156	1335	8558	5641	3752	3013	5651	4158	10041
	81%	81%	81%	81%	84%	77%	79%	83%	81%	82%	85%	82%	80%
None/ Don't know	471	111	232	73	11	44	288	184	114	85	153	115	356
	3%	2%	5%	2%	1%	3%	3%	3%	2%	2%	2%	2%	3%
TOTALS	51137	18062	14059	9985	4008	5022	31387	19750	13088	10812	20395	14193	36944
	291%	294%	289%	289%	291%	288%	290%	292%	283%	296%	306%	279%	295%

GALAXY RESEARCH  
TABLE 3 Standard Banner 1 \*BY\* C2 Understanding of mitochondrial disease  
BASE: WGHT SAMPLE (000s)  
WEIGHTS: Age/Sex/Area  
FILTERS: C1 Diseases - Aided Awareness(Mitochondrial disease)

	Sex		Age				Marital Status		Grocery Buyer		Children		Work Status			S.E.S.		
	Total	Male	Female	16-24	25-34	35-49	50+	Marr-ied	Not Marr-ied	Yes /Shared	No	Yes	No	Full Time	Part Time	Not Working	White	Blue
RESPONDENTS	367	196	171	51	37	150	129	214	153	256	111	151	216	173	88	106	242	125
WGHT SAMPLE (000s)	5705	3031	2674	885	845	1936	2040	3281	2424	3964	1741	2252	3453	2666	1393	1646	3775	1930
	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%
C2 Understanding of mitochondrial disease																		
A serious genetic disease that robs the body cells of energy and can affect various organs	2520 44%	1369 45%	1151 43%	525 59%	402 48%	884 46%	708 35%	1365 42%	1155 48%	1653 42%	867 50%	976 43%	1543 45%	1164 44%	555 40%	801 49%	1715 45%	804 42%
An autoimmune disease that primarily affects the valves of the heart	1237 22%	566 19%	671 25%	96 11%	104 12%	401 21%	636 31%	809 25%	428 18%	930 23%	306 18%	516 23%	720 21%	505 19%	352 25%	380 23%	700 19%	537 28%
An inflammatory disease that affects the cartilage and joints, impairing movement	485 9%	229 8%	256 10%	71 8%	93 11%	154 8%	167 8%	273 8%	212 9%	318 8%	167 10%	144 6%	342 10%	281 11%	126 9%	78 5%	298 8%	187 10%
An infectious disease spread by insects that leaves a person tired and fatigued	522 9%	257 8%	264 10%	95 11%	115 14%	197 10%	115 6%	358 11%	164 7%	396 10%	126 7%	232 10%	289 8%	223 8%	124 9%	175 11%	396 11%	125 6%
None/ Don't know	941 17%	610 20%	332 12%	97 11%	130 15%	300 15%	414 20%	477 15%	464 19%	667 17%	275 16%	383 17%	559 16%	492 18%	237 17%	213 13%	666 18%	276 14%
TOTALS	5705 100%	3031 100%	2674 100%	885 100%	845 100%	1936 100%	2040 100%	3281 100%	2424 100%	3964 100%	1741 100%	2252 100%	3453 100%	2666 100%	1393 100%	1646 100%	3775 100%	1930 100%

GALAXY RESEARCH  
TABLE 4 Standard Banner 2 \*BY\* C2 Understanding of mitochondrial disease  
BASE: WGHT SAMPLE (000s)  
WEIGHTS: Age/Sex/Area  
FILTERS: C1 Diseases - Aided Awareness(Mitochondrial disease)

	Total	State					Capital City		Household Income			Schooling	
		NSW	Vic/Tas	Qld	SA	WA	Yes	No	< \$40K	\$40K-\$69K	\$70K+	Below Year 12	Year 12
RESPONDENTS	367	115	96	61	44	51	243	124	78	82	163	68	299
WGHT SAMPLE (000s)	5705	2054	1496	1054	466	635	3706	1999	1185	1290	2493	1016	4689
	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%
C2 Understanding of mitochondrial disease													
A serious genetic disease that robs the body cells of energy and can affect various organs	2520 44%	1042 51%	619 41%	416 39%	144 31%	299 47%	1779 48%	740 37%	516 44%	490 38%	1123 45%	374 37%	2146 46%
An autoimmune disease that primarily affects the valves of the heart	1237 22%	449 22%	340 23%	178 17%	129 28%	140 22%	755 20%	482 24%	333 28%	313 24%	472 19%	270 27%	967 21%
An inflammatory disease that affects the cartilage and joints, impairing movement	485 9%	126 6%	129 9%	143 14%	68 15%	19 3%	262 7%	223 11%	40 3%	143 11%	240 10%	118 12%	367 8%
An infectious disease spread by insects that leaves a person tired and fatigued	522 9%	101 5%	140 9%	137 13%	76 16%	69 11%	297 8%	225 11%	130 11%	96 7%	252 10%	55 5%	467 10%
None/ Don't know	941 17%	336 16%	268 18%	180 17%	49 11%	108 17%	613 17%	328 16%	166 14%	247 19%	405 16%	199 20%	742 16%
TOTALS	5705 100%	2054 100%	1496 100%	1054 100%	466 100%	635 100%	3706 100%	1999 100%	1185 100%	1290 100%	2493 100%	1016 100%	4689 100%

GALAXY RESEARCH  
TABLE 5 Standard Banner 1 \*BY\* C2 Understanding of mitochondrial disease  
BASE: WGHT SAMPLE (000s)  
WEIGHTS: Age/Sex/Area

Based on All Respondents

	Total	Sex		Age				Marital Status		Grocery Buyer		Children		Work Status			S.E.S.	
		Male	Female	16-24	25-34	35-49	50+	Marr-ied	Not Marr-ied	Yes /Shared	No	Yes	No	Full Time	Part Time	Not Working	White	Blue
RESPONDENTS	1100	550	550	158	116	379	447	671	429	739	361	438	662	473	236	391	636	464
WGHT SAMPLE (000s)	17585	8580	9005	2723	2862	5004	6996	10572	7013	11727	5858	7006	10579	7449	3713	6423	10122	7463
	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%
C2 Understanding of mitochondrial disease																		
A serious genetic disease that robs the body cells of energy and can affect various organs	2520 14%	1369 16%	1151 13%	525 19%	402 14%	884 18%	708 10%	1365 13%	1155 16%	1653 14%	867 15%	976 14%	1543 15%	1164 16%	555 15%	801 12%	1715 17%	804 11%
An autoimmune disease that primarily affects the valves of the heart	1237 7%	566 7%	671 7%	96 4%	104 4%	401 8%	636 9%	809 8%	428 6%	930 8%	306 5%	516 7%	720 7%	505 7%	352 9%	380 6%	700 7%	537 7%
An inflammatory disease that affects the cartilage and joints, impairing movement	485 3%	229 3%	256 3%	71 3%	93 3%	154 3%	167 2%	273 3%	212 3%	318 3%	167 3%	144 2%	342 3%	281 4%	126 3%	78 1%	298 3%	187 3%
An infectious disease spread by insects that leaves a person tired and fatigued	522 3%	257 3%	264 3%	95 3%	115 4%	197 4%	115 2%	358 3%	164 2%	396 3%	126 2%	232 3%	289 3%	223 3%	124 3%	175 3%	396 4%	125 2%
None/ Don't know	12821 73%	6159 72%	6663 74%	1936 71%	2148 75%	3368 67%	5370 77%	7768 73%	5053 72%	8430 72%	4392 75%	5137 73%	7684 73%	5275 71%	2556 69%	4990 78%	7013 69%	5809 78%
TOTALS	17585 100%	8580 100%	9005 100%	2723 100%	2862 100%	5004 100%	6996 100%	10572 100%	7013 100%	11727 100%	5858 100%	7006 100%	10579 100%	7449 100%	3713 100%	6423 100%	10122 100%	7463 100%

GALAXY RESEARCH  
TABLE 6 Standard Banner 2 \*BY\* C2 Understanding of mitochondrial disease  
BASE: WGHT SAMPLE (000s)  
WEIGHTS: Age/Sex/Area

Based on All Respondents

	Total	State					Capital City		Household Income			Schooling	
		NSW	Vic/Tas	Qld	SA	WA	Yes	No	< \$40K	\$40K-\$69K	\$70K+	Below Year 12	Year 12
RESPONDENTS	1100	330	310	200	130	130	700	400	289	231	422	324	776
WGHT SAMPLE (000s)	17585	6147	4869	3450	1378	1741	10827	6758	4623	3659	6671	5082	12503
	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%
C2 Understanding of mitochondrial disease													
A serious genetic disease that robs the body cells of energy and can affect various organs	2520 14%	1042 17%	619 13%	416 12%	144 10%	299 17%	1779 16%	740 11%	516 11%	490 13%	1123 17%	374 7%	2146 17%
An autoimmune disease that primarily affects the valves of the heart	1237 7%	449 7%	340 7%	178 5%	129 9%	140 8%	755 7%	482 7%	333 7%	313 9%	472 7%	270 5%	967 8%
An inflammatory disease that affects the cartilage and joints, impairing movement	485 3%	126 2%	129 3%	143 4%	68 5%	19 1%	262 2%	223 3%	40 1%	143 4%	240 4%	118 2%	367 3%
An infectious disease spread by insects that leaves a person tired and fatigued	522 3%	101 2%	140 3%	137 4%	76 6%	69 4%	297 3%	225 3%	130 3%	96 3%	252 4%	55 1%	467 4%
None/ Don't know	12821 73%	4429 72%	3641 75%	2576 75%	961 70%	1214 70%	7734 71%	5087 75%	3604 78%	2616 72%	4583 69%	4266 84%	8556 68%
TOTALS	17585 100%	6147 100%	4869 100%	3450 100%	1378 100%	1741 100%	10827 100%	6758 100%	4623 100%	3659 100%	6671 100%	5082 100%	12503 100%



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For any questions  
or comments, please contact  
Peter Matthew  
at Galaxy Research.  
P + 61 2 9406 5812