

LDN Research Trust

A survey to monitor LDN as a treatment for MS

Eminent Neurologist Dr Alasdair Coles, from Addenbrooke's hospital in Cambridge
has given his approval and consent to this survey.

5th 100 Survey Statistics

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Together we can get LDN into clinical trials.

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LDN Survey Results

The results of the LDN Survey will be reported per 100 as they become available.

Q. Who is eligible to take part in the Survey?

A. Anyone with MS, who has or who is currently taking LDN.

Q. How are the people recruited to take part in the Survey?

A. Dr Lawrence has been sending out Survey Forms to all his patients with MS, who have ever taken LDN.

The MSRC printed in article in New Pathways asking people on LDN to contact us to take part in the Survey.

Friends of people with MS taking LDN have contacted us; many people taking LDN do not have a PC.

We have the Survey Form on our web site and on several MS and LDN web sites, others have a direct link.

Every survey form that has been returned to us has been inputted onto our data base; however we have no control over who chooses to reply.

Our aim is to keep the survey ongoing, it is still early days.

Type of MS	Benign	R&R	SP	PP	Still Taking	Neurologist/GP Recognise Improvement
	1%	44%	31%	23%	99%	40%

Dosage	1.5 mg	3 mg	4.5 mg	6 mg	Time Taken	21.00	22.00	23.00	24.00	1.00
	1%	28%	57%	1%		25%	53%	19%	1%	1%

Symptom Relief	Benign	R&R	SP	PP
85%	1%	37%	23%	19%

When did LDN Work	Day 1	D 2	D 3	D 4	Week 1	W 2	W 3	Month 1	M 2	M 3	M 8	Over 8 months
25% Unsure	13%	5%	7%	1%	15%	9%	4%	9%	8%	4%	1%	2%

Side Effects	1 S/E	2 S/E	3-5 S/E	Still	Vertigo Palpations	fatigue	Disturbed sleep	Increase in symptoms	Vivid Dreams	Bowel/Bladder Upset	Loss appetite hunger	Tingling/numbness	Nausea/upset stomach	Headache/Fuzzy head Weakness	Pain/Spasm	Stifness/spacity
61%	31%	16%	14%	15%	3%	1%	20%	1%	9%	6%	2%	2%	12%	17%	3%	14%

Further Progression	Benign	R&R	SP	PP
19%	0	7%	8%	4%

Stopped	No stalling of disability
1%	

Relapses Before	No. 1	No. 2	No. 3	More	Confirmed	Relapses After	No. 1	No. 4	Confirmed
49%	24%	18%	4%	4%	38%	18%	14%	2%	12%

Interferon Before	Interferon After	Wheat/Dairy Free Diet	Vitamins/Supplements
33%	1%	22%	76%

Who Prescribes	Dr Lawrence	Dr Bihari	Mexico	Neurologist	GP	USA	Other
	5%	6%	5%	11%	45%	13%	15%

When Started	1999	2001	2002	2003	2004	2005	2006
	1%	1%	1%	6%	13%	57%	21%

	Symptom gone	Improved greatly	Improved slightly	No Improvement	Increased greatly	Increased slightly	Never had this symptom
Bladder Urgency	9	33	24	13	0	6	15
Bladder Retention	3	28	12	22	2	0	33
Sexual Dysfunction	5	7	8	30	1	3	46
Bowel Control	5	10	11	25	2	1	46
Diarrhoea	6	4	2	8	0	1	79
Constipation	12	6	11	28	1	3	39
Memory	9	18	17	23	1	5	27
Concentration	9	18	22	18	1	4	28
Depression	11	20	13	19	2	5	30
Balance	10	15	33	26	2	11	3
Dizziness/Vertigo	14	12	16	21	2	5	30
Fatigue	7	39	30	12	3	7	2
Restless Legs	4	17	16	13	2	6	42
Sleep Disturbance	9	16	21	12	2	6	34
Hearing	5	3	3	18	0	2	69
Speech	6	5	10	16	0	1	62
Swallowing	5	6	4	15	0	4	66
Migraine type headache	5	4	10	11	0	4	66
Optic Neuritis	10	6	12	19	0	6	47
Blurred Vision	14	9	10	24	0	5	38
Double Vision	16	5	5	13	0	5	56
Mobility	7	20	24	30	2	7	10
Muscle Spasm	11	16	18	27	1	4	23
Muscle Strength	3	19	18	36	2	6	16
Muscle Pain	11	11	17	21	0	4	36
Tremor	9	6	11	19	4	8	43
Tingling	12	12	19	30	2	4	21
Itching	7	13	7	17	0	3	52
Numbness	17	12	18	35	3	3	12
Neuralgia	9	8	10	20	0	3	50