

Results from data received up to 1st February 2005

Questions	Total completed surveys	%	Total prior to diagnosis	%	Number of patients with symptoms since diagnosis	% of patients with new symptoms (after diagnosis)	% of patients with this symptom which appeared after diagnosis
	351	100.00%					
Gender							
Female	311	88.60%					
Male	40	11.40%					
Ages in 10 year groups							
Up to 30	63	17.95%					
31 to 40	131	37.32%					
41 to 50	114	32.48%					
51 to 60	45	12.82%					
61 and over	19	5.41%					
Country							
UK	60	17.09%					
USA	240	68.38%					
Poland	1	0.28%					
Brazil	1	0.28%					
Australia	16	4.56%					
Canada	18	5.13%					
India	1	0.28%					
South Africa	2	0.57%					
Spain	1	0.28%					
Egypt	1	0.28%					
New Zealand	2	0.57%					
Italy	1	0.28%					
Norway	1	0.28%					
Jamaica	1	0.28%					
Eire	1	0.28%					
Philippines	1	0.28%					
France	1	0.28%					
Israel	1	0.28%					
Information withheld on Country	1	0.28%					

Number of Doctors before diagnosis (mean average)	6						
Have you been diagnosed with MS	17	4.84%	15	4.27%	2	0.57%	11.76%
Have you been diagnosed with Lupus	69	19.66%	24	6.84%	45	12.82%	65.22%
Ocular							
Blurred or double vision	178	50.71%	0	0.00%	178	50.71%	100.00%
Visual disturbance	211	60.11%	128	36.47%	83	23.65%	39.34%
Visual loss	110	31.34%	73	20.80%	37	10.54%	33.64%
Retinal artery occlusion	17	4.84%	7	1.99%	10	2.85%	58.82%
Retinal vein thrombosis	11	3.13%	5	1.42%	6	1.71%	54.55%
Cardiorespiratory							
Chest pain	178	50.71%	115	32.76%	63	17.95%	35.39%
Radiating arm pain	118	33.62%	74	21.08%	44	12.54%	37.29%
Shortness of breath	170	48.43%	117	33.33%	53	15.10%	31.18%
Cardiac							
Insufficiency murmur	66	18.80%	35	9.97%	31	8.83%	46.97%
Myocardial infarction	47	13.39%	18	5.13%	29	8.26%	61.70%
Gastrointestinal							
Abdominal pain	162	46.15%	107	30.48%	55	15.67%	33.95%
Abdominal distension	164	46.72%	105	29.91%	59	16.81%	35.98%
Abdominal migraine	49	13.96%	35	9.97%	14	3.99%	28.57%
Emesis (vomiting)	54	15.38%	36	10.26%	18	5.13%	33.33%
Right upper quadrant	44	12.54%	31	8.83%	13	3.70%	29.55%
Abdominal tenderness	47	13.39%	29	8.26%	18	5.13%	38.30%
Pulmonary							
Respiratory distress	78	22.22%	53	15.10%	25	7.12%	32.05%
Tachypnea	53	15.10%	38	10.83%	15	4.27%	28.30%
Pulmonary embolism	67	19.09%	48	13.68%	19	5.41%	28.36%
Pulmonary hypertension	29	8.26%	14	3.99%	15	4.27%	51.72%
Peripheral Vascular							
Leg pain	213	60.68%	140	39.89%	73	20.80%	34.27%
Leg swelling	152	43.30%	103	29.34%	49	13.96%	32.24%
Claudication	148	42.17%	89	25.36%	59	16.81%	39.86%

Digital ulcerations	37	10.54%	19	5.41%	18	5.13%	48.65%
Leg ulcerations	20	5.70%	12	3.42%	8	2.28%	40.00%
Cold-induced finger and/or toe pain	159	45.30%	106	30.20%	53	15.10%	33.33%
Bone infarction	114	32.48%	75	21.37%	39	11.11%	34.21%
Avascular necrosis	109	31.05%	64	18.23%	45	12.82%	41.28%
Limb swelling (DVT)	106	30.20%	77	21.94%	29	8.26%	27.36%
Peripheral edema	56	15.95%	31	8.83%	25	7.12%	44.64%
Decreased capillary refill	30	8.55%	16	4.56%	14	3.99%	46.67%
Decreased pulses	34	9.69%	18	5.13%	16	4.56%	47.06%
Decreased perfusion	21	5.98%	12	3.42%	9	2.56%	42.86%
Gangrene	7	1.99%	5	1.42%	2	0.57%	28.57%
Musculoskeletal							
Bone pain	155	44.16%	97	27.64%	58	16.52%	37.42%
Joint pain	236	67.24%	153	43.59%	83	23.65%	35.17%
Cutaneous							
Purpuric and/or petechial rashes	37	10.54%	16	4.56%	21	5.98%	56.76%
Livedo reticularis	29	8.26%	15	4.27%	14	3.99%	48.28%
Dusky fingers and/or toes	49	13.96%	31	8.83%	18	5.13%	36.73%
Blanching of fingers and/or toes	57	16.24%	39	11.11%	18	5.13%	31.58%
Purpuric lesions	23	6.55%	11	3.13%	12	3.42%	52.17%
Superficial thrombophlebitis	40	11.40%	23	6.55%	17	4.84%	42.50%
Vasospasm	79	22.51%	56	15.95%	23	6.55%	29.11%
Splinter hemorrhages	14	3.99%	9	2.56%	5	1.42%	35.71%
Peripheral infarctions	11	3.13%	7	1.99%	4	1.14%	36.36%
Skin ulcerations	11	3.13%	7	1.99%	4	1.14%	36.36%
Bruising	34	9.69%	16	4.56%	18	5.13%	52.94%
Neurological and Psychiatric							
Syncope	54	15.38%	37	10.54%	17	4.84%	31.48%
Seizures	66	18.80%	41	11.68%	25	7.12%	37.88%
Headache (migraine)	253	72.08%	184	52.42%	69	19.66%	27.27%
Ascending weakness	137	39.03%	83	23.65%	54	15.38%	39.42%
Tremors	118	33.62%	72	20.51%	46	13.11%	38.98%
Memory loss	228	64.96%	121	34.47%	107	30.48%	46.93%
Problems with concentrating, reading comprehension, calculations (change in performance)	233	66.38%	129	36.75%	104	29.63%	44.64%
Stroke/CVA (cerebrovascular accident)	86	24.50%	55	15.67%	31	8.83%	36.05%

TIA	128	36.47%	74	21.08%	54	15.38%	42.19%
vasovasorum(or blood vessel) ischemia/infarction	77	21.94%	48	13.68%	29	8.26%	37.66%
Paralysis,	62	17.66%	35	9.97%	27	7.69%	43.55%
Abnormal movements	71	20.23%	38	10.83%	33	9.40%	46.48%
Multiple sclerosis-like disorder	140	39.89%	75	21.37%	65	18.52%	46.43%
Endocrine							
Weakness	212	60.40%	123	35.04%	89	25.36%	41.98%
Fatigue	268	76.35%	161	45.87%	107	30.48%	39.93%
Arthralgia	107	30.48%	71	20.23%	36	10.26%	33.64%
Abdominal pain	77	21.94%	47	13.39%	30	8.55%	38.96%
Adrenal infarction/hemorrhage	34	9.69%	19	5.41%	15	4.27%	44.12%
Genitourinary							
Hematuria (blood in urine)	55	15.67%	29	8.26%	26	7.41%	47.27%
Peripheral edema	64	18.23%	42	11.97%	22	6.27%	34.38%
Renal							
Hypertension	69	19.66%	29	8.26%	40	11.40%	57.97%
Renal artery thrombosis	8	2.28%	3	0.85%	5	1.42%	62.50%
Intrarenal vascular lesions (scar tissue)	16	4.56%	6	1.71%	10	2.85%	62.50%
Hematuria (blood in urine)	53	15.10%	26	7.41%	27	7.69%	50.94%
Renal vein thrombosis	7	1.99%	2	0.57%	5	1.42%	71.43%
Pregnancy Related							
Miscarriages (Number of Patients)	173	49.29%	173	49.29%	0	0.00%	0.00%
Premature birth (Number of Patients)	76	21.65%	57	16.24%	19	5.41%	25.00%
IUGR	30	8.55%	15	4.27%	15	4.27%	50.00%
Oligohydramnios	25	7.12%	17	4.84%	8	2.28%	32.00%
Chorea gravidarum	14	3.99%	8	2.28%	6	1.71%	42.86%
Placental infarction	37	10.54%	23	6.55%	14	3.99%	37.84%
Preeclampsia	54	15.38%	36	10.26%	18	5.13%	33.33%
Toxemia of pregnancy	40	11.40%	24	6.84%	16	4.56%	40.00%
Neonatal thromboembolism	11	3.13%	7	1.99%	4	1.14%	36.36%
Diagnosed APS during tests at pregnancy	153	43.59%	0	0.00%	0	0.00%	99.72%
Family History							
Pregnancy related family history	86	24.50%					

Family history of MI or stroke	56	15.95%	Relationship to pre or post diagnosis is immaterial
Family history of DVT, Phlebitis or PE	90	25.64%	
Family History of Migraine, Reynaud's or TIA's	123	35.04%	
Medical History			
Use of Oral Contraception during tests at pregnancy	98	27.92%	Relationship to pre or post diagnosis is immaterial
Other long-term use of medication	176	50.14%	
Vaccinations			
vaccinations	274	78.06%	Relationship to pre or post diagnosis is immaterial
Trauma or Stress Related			
Traumatic or stressful event prior to onset	258	73.50%	Relationship to pre or post diagnosis is immaterial

Other Symptoms

Back pain	16	4.56%
Pain in side of ribs (flank)	5	1.42%
Heat sensitivity	4	1.14%
Sun sensitivity	6	1.71%
Nasal ulcers	6	1.71%
Blood blisters in mouth	2	0.57%
Mouth ulcers	7	1.99%
Psoriatic Arthritis	2	0.57%
Muscle cramps	3	0.85%
Sinus problems	5	1.42%
Spontaneous bruising	4	1.14%
Thyroid problems (over/under active)	4	1.14%
Dizziness	15	4.27%
Constant headaches	14	3.99%

Notes and assumptions

As the questionnaire was specific in asking if a patient suffered from a symptom and if that symptom was there prior to diagnosis, I am making the assumption that the results in red have all appeared after diagnosis.

A further assumption is that on diagnosis treatment with Warfarin (Coumadin), Aspirin or both would have commenced. The figures then confirm that symptoms are still occurring post commencement of treatment. The disease is therefore degenerative, and the general opinion that symptoms disappear on treatment is little more than a figment of an over-imaginative mind, or the opinion of doctors who fail to follow their patients progress (or deterioration).

For Miscarriages and premature births I have included the number of patients who reported them and not a number of actual instances. A majority of these events led to diagnosis as a result of tests instigated after one, or many, pregnancy related problems

Many replies included lists of other diagnosed diseases and many symptoms that were already addressed in the questions. Wherever possible I have included these symptoms in the relevant question and used only those that are not previously listed as part of the 'Other Symptoms' listing.