

Gender	
Respondents	92
Male	49
Female	43
Mutations (all other mutations were represented by ≤ 3 subjects)	
Respondents	94
I692M	10
M1592V	19
R1448H	7
T1313M	5
T704M	27
Comorbid Conditions	
Thyroid	19
High blood pressure	19
Arrhythmias	9
Migraines	9
High triglycerides/cholesterol	8
Kidney problems	5
Diabetes, type 2	4
Coronary artery disease	3
Attention deficit disorder/Attention deficit hyperactivity disorder	1
Diabetes, type 1	0
Age of First Attack	
Respondents	84
Age 10-19	21
Diagnostic studies underwent prior to diagnosis of hyperPP	
Blood tests	63
EMG	46
EKG	30
Muscle biopsies	26
Urine tests	25
Nerve conduction study	22
Potassium challenge	22

Creatine kinase	17
Fasting challenge	16
Compound muscle action potential test	8
Ice water test	2

Concomitant Paramyotonia and/or Myotonia

Respondents	86
Paramyotonia	39
Paramyotonia + myotonia	24
Myotonia	48
Myotonia + paramyotonia	24
Myotonia + progressive muscle weakness	18
No myotonia	12
No myotonia + progressive muscle weakness	4

Attack Triggers

Total respondents	91
Female respondents	43
Cold environments	69
Rest after exercise	61
Stress or fatigue	43
Alcohol	41
Hunger	39
Changes in activity level	37
Potassium in food	32
Specific foods or beverages	32
Changes in humidity	32
Extra sleep	31
Pregnancy	12
Illness of any type	24
Menstruation	8
Medication	15
Potassium supplements	13

Typical time of day of attack occurrence

Respondents	86
Morning	48

During sleep	39
Upon waking	37
Afternoon	25
Evening	17

Prodromal symptoms

Respondents	70
Day prior: positive response	27
Immediately prior: positive responses	60

Attack frequency

Respondents	87
1-3 per month	26
1 per week	18
2-6 per week	21

Typical attack duration

Respondents	80
<5 min	8
5-15 minutes	3
15-30 minutes	11
30 minute to an hour	17
1-2 hours	5
3-4 hours	5
10-15 hours	2
20 hours-1 day	4
1-2 days	8
>2 days	17

Longest attack

Respondents	83
Over 1 week	19

Body region affected by attack

Respondents	92
Calves	86
Arms	84

Hands	83
Thighs	83
Feet	70
Eyelids	58
Face	57
Neck	54
Speaking musculature	53
Hips	39
Breathing musculature	24
Trunk	5

Severity of most attacks

Respondents	90
Very mild – barely noticeable to others, few limitations	5
Mild – have only some limitations on mobility, others would notice I am in an attack	39
Moderate – have some movement, can self-medicate	32
Severe – can speak, cannot move at all, can call for help	12
Very severe – cannot speak, cannot call for help	2

Severity of interictal symptoms

Respondents	89
Severe, impairs activities of daily living	11
Moderate	12
Mild	30
No symptoms	36

Muscle pain

Respondents	92
Muscle pain during attacks	38
After attacks	57
None	24

Frequency of attacks over time

	Worsened	Stayed the same	Improved
Childhood	64	6	0
Puberty/teenage years	31	5	3
20-39	12	7	4
40-69	9	3	3

70+	1	0	0
Menopause	1	0	2

Muscle stiffness during attacks	Worsened	Stayed the same	Improved
Childhood	40	7	0
Puberty/teenage years	14	6	3
20-41	5	5	5
40-71	6	3	2
70+	0	0	0
Menopause	2	0	1

Muscle weakness during attacks	Worsened	Stayed the same	Improved
Childhood	5	10	0
Puberty/teenage years	4	7	6
20-40	4	6	18
40-70	8	1	11
70+	1	0	0
Menopause	0	0	1

Permanent muscle weakness	Worsened	Stayed the same	Improved
Childhood	18	8	0
Puberty/teenage years	4	8	0
20-42	3	7	0
40-72	10	1	0
70+	1	1	0
Menopause	0	2	0

Progressive myopathy (muscle dysfunction) or permanent weakness	
Respondents	92
Yes	28
No	48
Unsure	16

Level of Disease Control	
Respondents	83
Mostly controlled	37
Needs improvement	42

Optimal	4
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Acute Medications	Mostly Controlled	Needs Improvement
Respondents	14	20
None	2	4
Hydrochlorothiazide	2	5
Salbutamol	2	4
Mexiletine	2	1
Flecainide	2	0
Furosemide	1	0
Acetazolamide	1	4
Magnesium	1	3
Torsemide	1	0
Fenoterol	1	0
Orphenadrine	1	0
Nonsteroidal anti-inflammatory drugs	1	1
Calcium	1	1
Carbamazepine	0	1
Potassium	0	1
Propafenone	0	1
Muscle relaxants	0	1

Chronic Medications	Mostly Controlled	Needs improvement
Respondents	23	26
Hydrochlorothiazide	5	4
Mexiletine	5	1
No treatment regimen	4	16
Flecainide	3	0
Acetazolamide	2	5
Salbutamol	2	1
Fludrocortisone	1	1
Magnesium	1	1
Torsemide	1	0
Furosemide	1	1
Omeprazole	1	0
Vitamin C	1	0
Limptar	1	0

Salt	1	0
Potassium	0	1
Electrolyte fluid	0	1

Able to abort an attack

Respondents	86
Never	18
Occasionally	13

Episodes of weakness that improve with potassium intake

Respondents	63
Positive	8

Years to arrive at current regimen

Respondents	22
10+ years	12
5-10 years	5
1-5 years	6
<1 year	2

Pregnancy	Worsened	Stayed the same	Improved
Frequency of attacks over time	11	0	1
Muscle stiffness during attacks	6	0	2
Muscle weakness during attacks	1	0	4
Permanent muscle weakness	1	2	0

Effects of surgery

Respondents	74
Never had surgery	17
Non-anesthetic surgical complications	13

Effects of local anesthesia

Respondents	83
Never had local anesthesia	7
Complications related to local anesthesia	8

Effects of general anesthesia

Respondents	86
Never had general anesthesia	19
Complications related to general anesthesia	20
