**Appendix e-1 Prednisone-Steroid Use and MG Survey**

1. **Are you currently taking steroid (prednisone) for your myasthenia gravis?**

□1=Yes □2=No □99= Unknown

 ***1.a.******If yes, what is the total daily dose:*** \_\_ \_\_ \_\_ . \_\_mg*[Enter 999.9 for dose if unknown]*

***If you take prednisone every other day, divide the “every other day” dose by 2 and record that amount. E.g., If you take 80 mg every other day, you would divide that dose by 2 and you would record 40.***

 ***1.b. What is the dosing frequency of your steroid (prednisone)?***

□1=One time a day

 □2=One time every other day

 □3=Other, specify\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

1. **Have you taken steroid (prednisone) in the past for your myasthenia gravis?**

□1=Yes □2=No □99= Unknown

***If both #1 and #2 are No or Unknown, survey ends here.***

***If either #1 or #2 is Yes, please continue.***

1. **How long have you been on steroid (prednisone) for your MG, current and/or past? Please estimate total number of months:** \_\_ \_\_ \_\_

1. **What is the highest total daily dose of steroid (prednisone) you have taken? Again, if you take prednisone every other day, divide the “every other day” dose by 2, to identify your daily dose.**

\_\_ \_\_ \_\_ . \_\_mg

1. **What was the dosing frequency at the time of your maximum/highest dosage?**

□1=One time a day

□2=One time every other day

□3=Other, specify\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

 □99=Unknown

1. **How long did you take that highest dose of steroid (prednisone)? If currently taking highest dose to date, indicate how long you have been taking it so far.**

□1= Less than 2 weeks

□2= More than 2 weeks less than 1 month

□3= More than 1 month less than 3 months

□4= More than 3 months

1. **What was your age at the time you took the highest dose of steroid (prednisone)?** \_\_ \_\_
2. **What was the reason when your steroid dose was lowered from the highest dose?**

□1=Still on highest dose to date

□2=Symptom(s) well controlled

□3=Unable to tolerate side effect(s)

□4=Both 2 and 3

□5=Other, specify: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

1. **Have you experienced any side effects from taking the steroid (prednisone)?**

□1=Yes □2=No □3= Unsure

***9.a.******If yes, what side effects have you experienced from taking steroid (prednisone)?***

***Select all that apply:***

|  |  |  |
| --- | --- | --- |
| □=acne□=back pain□=bruises□=changed appearance□=changed taste□=decreased interest in sex□=depression□=diabetes mellitus/elevated  blood sugar□=diarrhea□=fatigue□=fracture□=fragile skin | □=gingival hyperplasia  (gum swelling)□=headache□=high blood pressure□=impotence/ painful menstruation□=increased appetite□=increased hair growth□=inflammation□=mood swings□=moon face | □=painful/inflamed /prominent scar□=palpitations□=persistent chest pain□=poor appetite□=poor concentration□=poor vision□=serious infection□=sleeplessness□=stomach complaints□=swollen ankles□=tremor□=weight gain |

***9.b.******If yes, are /were any of the side effects of steroid (prednisone) difficult to tolerate?***

***Select all that apply:***

|  |  |  |
| --- | --- | --- |
| □=no, none□=acne□=back pain□=bruises□=changed appearance□=changed taste□=decreased interest in sex□=depression□=diabetes mellitus/elevated  blood sugar□=diarrhea□=fatigue□=fracture□=fragile skin | □=gingival hyperplasia  (gum swelling)□=headache□=high blood pressure□=impotence/ painful menstruation□=increased appetite□=increased hair growth□=inflammation□=mood swings□=moon face | □=painful/inflamed /prominent scar□=palpitations□=persistent chest pain□=poor appetite□=poor concentration□=poor vision□=serious infection□=sleeplessness□=stomach complaints□=swollen ankles□=tremor□=weight gain |

1. **If your myasthenia gravis symptoms worsen, are you willing to try a dose of steroid (prednisone) higher than your current dose or to start steroid if not on it currently?**

 □1=Yes □2=No □3=Depends on symptom severity □4=Unsure

1. **If your myasthenia gravis symptoms worsen significantly, are you willing to try your previous highest dose steroid (prednisone) or, if currently on your highest dose to increase it further?**

 □1=Yes □2=No □3=Depends on symptom severity □4=Unsure