| General description of dystonia | Activities that worsen dystonia | Body part affected by dystonia |
|---------------------------------|---------------------------------|-------------------------------|
| 'All the time when meds wear off.' | 'No specific activities.' | 'Both feet. Toes curl.' |
| 'Unclear to participant. It seems random.' | 'Standing, walking, resting.' | 'Left, middle, fingers, and toes on right foot. Right fingers will draw.' |
| 'Leg morning and evening (morning before medicines work).' | 'Ocular is brought on by bright lights. Leg activity is brought on if he thinks about it' | 'Leg and eye' |
| 'Every 4 hours when meds wear off' | 'She experiences it at rest.' | 'Right toes. Right leg. Both wrists. Her neck.' |
| 'Shortly after dose of medicine until it starts wearing off.' | 'Sitting, at rest' | 'Left foot' |
| 'Only notice it when sitting on couch watching TV at the end of the day' | 'Only notice it when resting' | 'Left and right feet areas affected' |
| 'When tired.' | 'Walking will bring it on' | 'Left foot' |
| 'Does not happen at specific time of day' | 'Sitting and rest' | 'Both legs' |
| '1st thing in the morning when meds are off.' | 'At rest, also hands will activate if reading or holding something; Foot at rest, with meds off.' | 'Both feet, both hands/wrists and neck.' |
| 'Afternoon' | 'At rest' | 'Neck' |
| 'When medicines are off' | 'Anything that requires continuous effort/force' | 'Right side hand and toes' |
| 'When medicines wear off' | 'Rest' | 'Neck, trunk, right arm and right foot' |
| 'All the time.' | 'Always.' | 'Left toes and neck.' |
| 'Starts after participant takes the first dosage of medicine' | 'At rest' | 'Left leg' |
| 'Night, afternoon' | 'Lack of sleep, lack of exercise.' | 'Right shoulder, hip, foot' |
| 'Occurs often' | 'Walking, anxiety' | 'Right foot' |
| 'Does not occur often' | 'Rest' | 'Left arm' |

SUPPLEMENTARY TABLE 1. Patient experiences with dystonia surveyed pre-surgery.