**Introductory Email (not in the survey)**

We are contacting you because you are an experienced botulinum toxin A (BoNT-A) injector practising in Canada to see if you would be willing to fill out an anonymous survey regarding your real-world experience treating paratonia in the community or Long-Term Care (LTC) Facility. The purpose of the survey is to better understand current treatment approaches to paratonia, an off-label indication for BoNT-A and understand the regional barriers to treating this condition.

While this is an anonymous survey, you will have an opportunity at the end of the survey, to click on a link to provide your name and contact information if you are interested in participating in further research regarding paratonia and be involved in creating practise parameters as part of a Delphi process. The survey will take approximately 10 minutes to complete.

**Canadian Physician and Allied Health Professional Paratonia in Dementia Treatment Survey**

The purpose of this survey is to determine current practises regarding injection of botulinum toxin A (BoNT-A) to address paratonia in those with dementia in long term care (LTC) homes and in the community.

Most individuals with advanced dementia will manifest paratonia to variable degrees and in variable limbs.

Paratonia is currently an “off-label” indication for BoNT-A, but preliminary studies have demonstrated significant improvement in involuntary postures, patient comfort, care-giver burden, and anticipated prevention of contractures, pressure ulcers, and pain.

We are performing a survey to determine awareness of paratonia, current treatment patterns, and to define the unmet need of those with dementia and paratonia to inform quality improvement initiatives for patients with dementia and paratonia in Canada, the UK, and other parts of Europe.

Participation in the survey is anonymous and voluntary. There are no risks to participating in the survey. Your responses will be treated confidentially. Data collected in this survey will be used in aggregate form to inform future clinical and research initiatives including publication in peer-reviewed journals and inform future potential for commercialization. Baycrest Health Sciences and Dr. G. Kleiner hold use patents for botulinumtoxin in paratonia.

Completion of the survey will be viewed as consent to participate in this research.

Investigators:

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This research was reviewed and approved by the Baycrest Research Ethics Board

You can reach them with any concerns by calling 416-785-2500 x2440

You can reach Dr. Galit Kleiner at [Gkleiner@baycrest.org](mailto:Gkleiner@baycrest.org) or 416-785-2500 ext 2715

1. Please identify your professional designation:
   1. Neurologist
   2. Physiatrist
   3. Other (specify) \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
2. Where do you work (province)?
   1. British Columbia
   2. Alberta
   3. Saskatchewan
   4. Manitoba
   5. Ontario
   6. Quebec
   7. Nova Scotia
   8. Prince Edward Island
   9. New Brunswick
   10. Newfoundland and Labrador
   11. Northwest Territories
   12. Yukon
   13. Nunavut
3. How is paratonia different from spasticity?

(free text)

1. In what setting do you see patients with paratonia?
   1. Clinic
   2. Long Term Care (LTC)
   3. Acute care hospital
   4. Rehabilitation hospital
   5. Other (Specify)\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
2. What treatment modalities do you use to treat patients with paratonia (tick all that apply)?
   1. Passive range of motion exercise
   2. Positioning
   3. Cushions
   4. Baclofen
   5. Tizanidine
   6. Dantrolene
   7. Benzodiazepine
   8. BoNT-A
   9. Combination (please specify) \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

If you treat patients with increased tone with BoNT-A go to **question 6**

If you don’t treat patients with increased tone with BoNT-A go to **question 21**

1. How many years have you been injecting BoNT-A?
   1. 0-5 years
   2. 5-10 years
   3. 10-15 years
   4. 15-20 years
   5. >20 years
2. **In LTC**, what indications do you treat with BoNT-A?
   1. I don’t treat patients in LTC
   2. I don’t treat with BoNT-A in LTC
   3. I treat with BoNT-A in LTC (please provide as many indications that you treat and in what proportion for a total of 100%)
      1. Spasticity (\_%)
      2. Dystonia (\_%)
      3. Blepharospasm or Hemifacial spasm (\_%)
      4. Paratonia (\_%)
      5. Cervical dystonia (\_%)
      6. Other (Specify) (\_%)
3. **In your office/clinic**, what indications do you treat with BoNT-A and in what proportion?
   1. I don’t treat with BoNT-A in my office/clinic
   2. I treat with BoNT-A in LTC (please provide as many indications that you treat and in what proportion for a total of 100%)
      1. Spasticity (\_%)
      2. Dystonia (\_%)
      3. Blepharospasm or Hemifacial spasm (\_%)
      4. Paratonia (\_%)
      5. Other (Specify) (\_%)
4. **In a rehabilitation facility or acute care hospital**, what indications do you treat with BoNT-A and in what proportion?
   1. I don’t treat patients in a rehabilitation facility or an acute care hospital
   2. I don’t treat with BoNT-A in an acute care hospital or rehabilitation facility
   3. I treat with BoNT-A in a rehabilitation facility or an acute care hospital (please provide as many indications that you treat and in what proportion for a total of 100%)
      1. Spasticity (\_%)
      2. Dystonia (\_%)
      3. Blepharospasm or Hemifacial spasm (\_%)
      4. Paratonia (\_%)
      5. Other (Specify) (\_%)
5. **In LTC**, how many patients with paratonia/month on average did you treat with BoNT-A in the last year?
   1. 0
   2. 1-5
   3. 5-10
   4. 10-20
   5. 20-30
   6. 40-50
   7. >50
6. **In your office/clinic**, how many patients with paratonia/month on average did you treat with BoNT-A in the last year?
   1. 0
   2. 1-5
   3. 5-10
   4. 10-20
   5. 20-30
   6. 40-50
   7. >50
7. **In a rehabilitation facility or acute care hospital**, how many patients with paratonia/month on average did you treat with BoNT-A in the last year?
   1. 0
   2. 1-5
   3. 5-10
   4. 10-20
   5. 20-30
   6. 40-50
   7. >50
8. How many years have you been treating patients for paratonia with BoNT-A?
   1. I don’t treat patients with paratonia
   2. I don’t treat patients with paratonia with BoNT-A
   3. 0-1 year
   4. 1-5 years
   5. 5-10 years
   6. 10-15 years
   7. 15-20 years
   8. >20 years
9. When you treat patients with paratonia with BoNT-A what brand of toxin do you use?
   1. Not applicable (N/A) I don’t treat patients with paratonia with BoNT-A
   2. IncobotulinumtoxinA (Xeomin) (\_%)
   3. OnabotulinumtoxinA (Botox) (\_%)
   4. AbobotulinumtoxinA (Dysport) (\_%)
10. On average, how many units of BoNT-A do you use per patient with paratonia/injection session?
    1. Not applicable (N/A) I don’t treat patients with paratonia with BoNT-A
    2. \_\_\_\_ Ona/IncobotulinumtoxinA units
    3. \_\_\_\_ AbobotulinumtoxinA units
11. What criteria do you use to determine when to initiate BoNT-A for paratonia? (mark all that apply)
    1. Not applicable (N/A) I don’t treat patients with paratonia with BoNT-A
    2. Modified Ashworth Scale (MAS). If yes what grade?
       1. 1
       2. 2
       3. 3
       4. 4
    3. Caregiver burden scale (CBS)
    4. Request from caregiver (family or professional)
    5. Complications
       1. Presence of pressure ulcer due to involuntary posture
       2. Pain when manipulating limb
       3. Caregiver burden (involuntary postures interfering in care like toileting, cleaning, dressing etc.)
       4. Difficulty positioning patient or applying splint due to involuntary posture
       5. Contractures
       6. Others (Specify) \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
12. When you inject for paratonia what postures do you treat (check all that apply)?
    1. Not applicable (N/A) I don’t treat patients with paratonia with BoNT-A
    2. Clenched fist (\_\_\_%)
    3. Adducted shoulder (\_\_\_%)
    4. Flexed elbow (\_\_\_%)
    5. Extended elbow (\_\_\_%)
    6. Flexed wrist (\_\_\_%)
    7. Flexed knees (\_\_\_%)
    8. Extended knees (\_\_\_%)
    9. Adducted thighs (\_\_\_%)
    10. Plantar flexion (\_\_\_%)
    11. Ankle intorsion (\_\_\_%)
    12. Toe flexion/extension (\_\_\_%)
    13. Other (Specify) (\_\_\_%)
13. What outcome measures do you use when treating patients with paratonia with BoNT-A? (mark all that apply)
    1. Not applicable (N/A) I don’t treat patients with paratonia with BoNT-A
    2. Disability assessment scale (DAS)
    3. Caregiver burden scale (CBS)
    4. Clinical global impression (CGI)
    5. SMART goals
    6. Modified Ashworth Scale (MAS)
    7. Goniometer measures of angle
    8. Subjective reporting of caregiver
    9. Subjective overall impression
    10. Other (please specify)
14. In general, what outcomes have you observed when treating patients with BoNT-A?
    1. Not applicable (N/A) I don’t treat patients with paratonia with BoNT-A
    2. No clinically relevant improvement
    3. Slight improvement
    4. Moderate clinically relevant improvement
    5. Significant clinically relevant improvement
    6. Describe specific impact of treatment (eg less pain, easier to provide hygiene, etc)
15. Were there side effects of BoNT-A treatment for paratonia?
    1. Not applicable (N/A) I don’t treat patients with paratonia with BoNT-A
    2. None
    3. Bruising
    4. Indications of pain at the site of injection
    5. Excess weakness in a limb leading to loss of function
    6. Swallowing impairment
    7. Distal spread
    8. Other (please specify)
16. Can your patients access funding for BoNT-A for paratonia y / n

If yes how is BoNT-A for paratonia funded in your province?

* 1. Exceptional access program through province (\_\_\_%)
  2. Private pay (\_\_\_%)
  3. Private health insurance (\_\_\_%)
  4. Compassionate use from drug company (\_\_\_%)
  5. Prescribe BoNT-A for spasticity for which an indication exists if there is any history of TIA/vascular disease

1. Do you think there are barriers to treatment of those with dementia and paratonia with BoNT-A? Y/N? (If yes, check all that apply)
   1. Lack of awareness or recognition of paratonia
   2. Belief that paratonia is not treatable
   3. Lack of awareness of BoNT-A as a possible effective treatment
   4. Off-label (only would treat an on-label indication)
   5. Lack of re-imbursement for BoNT-A for this off-label indication
   6. Concern for safety (not enough research)
   7. Not enough qualified physicians to provide injections
   8. Satisfied with passive range of motion therapy or other non-pharmacologic treatments for paratonia (cushions/positioning etc.)
   9. Logistical barriers to seeing paratonia patients in LTC
      1. Logistics of travelling to long-term care institutions
      2. Lack of mobile clinics or infrastructure in LTC to perform efficient injections
   10. Other (Specify) \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
2. Do you feel that there is an unmet need with respect to treating paratonia with BoNT-A?
   1. Yes
   2. No
3. In your opinion, what proportion of **LTC residents** with paratonia that would benefit from BoNT-A are not being treated with BoNT-A?
4. In your opinion, what proportion of **clinic/community patients** with paratonia that would benefit from BoNT-A are not being treated with BoNT-A?
5. In your opinion, what proportion of **acute care/rehabilitation hospital patients** with paratonia that would benefit from BoNT-A are not being treated with BoNT-A?
6. Would you be interested in participating in a Delphi process to guide practise parameters for treatment of paratonia with BoNT-A? If yes please click on the link below to provide your name and email address. Your contact information will not be linked to survey results which will remain anonymous.

**Thank you very much for completing the survey**