



Common Drug Review *Patient Group Input Submissions*

Indacaterol/glycopyrronium (Ultibro Breezhaler) for Chronic Obstructive Pulmonary Disease (COPD)

Patient group input submissions were received from the following patient groups. Those with permission to post are included in this document.

COPD Canada – permission not granted to post

Ontario Lung Association — permission granted to post.

CADTH received patient group input for this review on or before July 23, 2014

CADTH posts all patient input submissions to the Common Drug Review received on or after February 1, 2014 for which permission has been given by the submitter.

The views expressed in each submission are those of the submitting organization or individual; not necessarily the views of CADTH or of other organizations. While CADTH formats the patient input submissions for posting, it does not edit the content of the submissions.

CADTH does use reasonable care to prevent disclosure of personal information in posted material; however, it is ultimately the submitter's responsibility to ensure no personal information is included in the submission. The name of the submitting patient group and all conflict of interest information are included in the posted patient group submission; however, the name of the author, including the name of an individual patient or caregiver submitting the patient input, are not posted.

COPD Canada

Section 1 — General Information

Name of the drug CADTH is reviewing and indication(s) of interest	Ultibro Breezhaler indacaterol/glycopyrronium
Name of the patient group	COPD Canada
Name of the primary contact for this submission:	[REDACTED]
Position or title with patient group	[REDACTED]
Email	[REDACTED]
Telephone number(s)	[REDACTED]
Name of author (if different)	
Patient group's contact information: Email	[REDACTED]
Telephone	[REDACTED]
Address	555 Burnhamthorpe Rd., Suite 306 Toronto, ON M9C 2Y3
Website	www.copdcanada.info
Permission is granted to post this submission	No

The patient group has not granted permission to post its patient input submission. As announced in [CDR Update — Issue 99](#), when permission is not granted, CADTH will post on its website that a patient submission was received, but it was not posted at the request of the submitter.

The patient input that was provided in this submission, along with all other patient input received for this drug, is included in the summary of patient input that is contained in the posted *CDR Clinical Review Report*.

Ontario Lung Association

Section 1 — General Information

Name of the drug CADTH is reviewing and indication(s) of interest	Name = Ultibro Breezhaler / Indacaterol glycopyrronium Indication = Chronic Obstructive Pulmonary Disease (COPD)
Name of the patient group	Ontario Lung Association
Name of the primary contact for this submission:	██████████
Position or title with patient group	██████████
Email	██████████
Telephone number(s)	██████████
Name of author (if different)	
Patient group's contact information: Email	info@on.lung.ca
Telephone	416-864-9911 or 1-800-344-5864
Address	18 Wynford Drive, Suite #401, Toronto, ON M3C 0K8
Website	www.on.lung.ca
Permission is granted to post this submission	Yes

1.1 Submitting Organization

The Ontario Lung Association is a registered charity that assists and empowers people living with or caring for others with lung disease. It is a recognized leader, voice and primary resource in the prevention and control of respiratory illness, tobacco cessation and prevention, and air quality and its effects on lung health. The Association provides programs and services to patients and health-care providers, invests in lung research and campaigns for improved policies on lung health. It is run by a board of directors and has approximately 70 employees, supported by thousands of dedicated volunteers and working out of a provincial office in Toronto and nine community offices throughout Ontario.

1.2 Conflict of Interest Declarations

a) Regarding corporate members and joint working, sponsorship, or funding arrangements:

The Ontario Lung Association receives sponsorship and grants from a number of for-profit companies which support educational and research initiatives. Companies who provide funding to the Ontario Lung Association include: Pfizer, GlaxoSmithKline, Boehringer Ingelheim, AstraZeneca, Merck, Novartis, Takeda, InterMune, Grifols, Actelion, Astellas, Bayer, J&J, OHRSA, Roche, RX&D, Valent Pharmaceuticals and Eli Lilly. None of these organizations participated in any way in this submission.

b) Regarding those playing a significant role in compiling this submission:

(Nothing to declare)

Section 2 — Condition and Current Therapy Information

2.1 Information Gathering

The information provided in section two was obtained from an on-line survey sent to patients and their caregivers (to which we received 146 responses), several one-to-one phone conversations with patients, a certified respiratory educator, and previous patient surveys completed by the Ontario Lung Association.

2.2 Impact of Condition on Patients

The symptoms and problems that patients experience as a result of COPD are many, but at the top of the list were shortness of breath, difficulty breathing, coughing, and fatigue. Tasks like walking up stairs, opening doors or getting the mail causes shortness of breath. Low energy, mucus/wheezing and difficulty sleeping are also common problems. Pain in the chest was also cited. COPD lowers immunity and infections were noted as ongoing issues as was their mood /emotional well-being. The need for oxygen and medications are constant and the inability to do daily activities like housework, cooking or shopping leave some people feeling depressed, frustrated and without hope. COPD impacts almost all aspects of day-to-day life for people living with it. It affects: the ability to participate in physical and leisure activities, the ability to work, travel and socialize. It also affects relationships with family and friends, independence, and for many their financial situation. Having to retire/leave the work force was mentioned several times. COPD slowly robs people of their independence.

2.3 Patients' Experiences With Current Therapy

Treatments tried by those interviewed included: Spiriva, Advair, Symbicort, Daxas, Prednisone, Ventolin, Atrovent, Serevent, Seebri, Onbrez, and a few had recently tried Breo Ellipta.

Current treatments do provide some relief for: fatigue, shortness of breath, cough, appetite loss, low energy, and the inability to fight infection, but the side effects such as: palpitations, dry mouth, mouth sores, visual and urinary problems and impact on mood need to be better managed.

The desire for fewer medical appointments was mentioned several times, as was a wish for less cost burden. Current therapies do not reduce mucus production enough or hold oxygen levels high enough. Overall, patients would like their treatments to provide enough help that they will experience improved independence and require less assistance from others.

2.4 Impact on Caregivers

Caregivers of those living with COPD experience many of the same negative impacts on their lives. They too indicate that caring for people with COPD has affected their work, their relationships with family and friends, and their physical and leisure activities. As well, their independence and the ability to travel and socialize were impacted. Having to take time off work to drive those they are caring for to get groceries, run errands or make medical appointments was cited as problematic for caregivers.

Section 3 — Information about the Drug Being Reviewed

3.1 Information Gathering

The information provided in section two was obtained from an on-line survey sent to patients and their caregivers (to which we received 146 responses), several one-to-one phone conversations with patients, a certified respiratory educator, and previous patient surveys completed by the Ontario Lung Association.

3.2 What Are the Expectations for the New Drug or What Experiences Have Patients Had With the New Drug?

a) Based on no experience using the drug:

Key treatment outcomes of COPD that patients and their caregivers would most like addressed are: to reduce shortness of breath, reduce coughing, reduce fatigue and improve appetite. They would like an increased ability to fight infection and have a higher energy level. Ideally, patients would experience an improved quality of life, improved lung function and reduced hospital admissions.

Patients indicated that they would be able to live with some side effects, but nothing worse than they are already experiencing and nothing that was irreversible.

Patients do not want to travel to a health-care setting to receive new treatments. They do not want to have to make additional changes to daily routines for themselves or their caregivers and do not want anyone to have to take time off work to accommodate treatments. Patients want to improve enough so that they will be less of a burden to their family.

Finally, patients would like there to be less or no cost burden associated with new treatments.

b) Based on patients' experience with the new drug as part of a clinical trial or through a manufacturer's compassionate supply:

No patients within this evidence group submission have used the drug Ultibro Breezhaler / Indacaterol glycopyrronium.

Section 4 — Additional Information

All patients indicated that shortness of breath was the symptom they would most like to reduce. Patients would like to be less dependent on oxygen. Patients also indicated that they would like to know more about new treatments for their condition – when they become available / how to be a part of trials or experimental groups. Many patients also expressed interest in accessing information on new therapies.