Extracorporeal Photopheresis (ECP) for the Management of Progressive Bronchiolitis Obliterans Syndrome (BOS) in Medicare-Eligible Recipients of Lung Allografts

QUALITY OF LIFE - Case Report Form (CRF)

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Quality of Life Date:

SECTION 1 Modified Medical Research Council Dyspnea Scale

Please circle the grade that best fits your usual condition these days. Only circle one grade.
Grade Symptoms

Grade Symptoms

- **0 Not troubled with breathlessness except with strenuous exercise**
- **1 Troubled by shortness of breath when hurrying on the level or walking up a slight hill**
- **2 Walks slower than people of the same age on the level because of breathlessness or has to stop for breath when walking at own pace on the level**
- **3 Stop for breath after walking about 100 yards or after a few minutes on the level**
- **4 Too breathless to leave the house or breathless when dressing or undressing**

SECTION 2 ST. GEORGE'S RESPIRATORY QUESTIONNAIRE For COPD patients (SGRQ-C)

This questionnaire is designed to help us learn much more about how your breathing is troubling you and how it affects your life.

We are using it to find out which aspects of your illness cause you most problems, rather than what the doctors and nurses think your problems are.

Please read the instructions carefully and ask if you do not understand anything. Do not spend too long deciding about your answers.

Please select one to show how you describe your current health:

- **Very good**
- **Good**
- **Fair**
- **Poor**
- **Very poor**

Questions about how much respiratory trouble you have.

Please check ONE box for each question:

1. I cough:

- **most days a week**
- **several days a week**
- **only with respiratory infections**
- **not at all**

2. I bring up phlegm (sputum):

- ○ most days a week
- ○ several days a week
- ○ only with respiratory infections
- ○ not at all

3. I have shortness of breath:

- ○ most days a week
- ○ several days a week
- ○ not at all

4. I have attacks of wheezing:

- ○ most days a week
- ○ several days a week
- ○ a few days a month
- ○ only with respiratory infections
- ○ not at all

5. How many attacks of respiratory attacks did you have during this last year?

- ○ 3 or more attacks
- ○ 1 or 2 attacks
- ○ none

6. How often do you have good days (with few respiratory problems)?

- ○ no good days
- ○ a few good days
- ○ most days are good
- ○ every day is good

7. If you have a wheeze, is it worse in the morning?

- ○ No
- ○ Yes

8. How would you describe your respiratory problems? (Please select one)

- ○ Causes me a lot of problems or is the most important problem I have
- ○ Causes me a few problem
- ○ Causes no problem

9. Questions about what activities usually make you feel breathless. For each statement please select the box that applies to you these days:

○ True	○ False	Getting washed or dressed
○ True	○ False	Walking around the home
○ True	○ False	Walking outside on level ground
○ True	○ False	Walking up a flight of stairs
○ True	○ False	Walking up hills

10. Some more question about your cough and breathlessness (if you have either). For each statement please select the box that applies to you these days:

- ○ True ○ False My cough hurts
- ○ True ○ False My cough make me tired
- ○ True ○ False I am breathless when I talk
- ○ True ○ False I am breathless when I bend over
- ○ True ○ False My cough or breathing disturbs my sleep
- ○ True ○ False I get exhausted easily

11. Questions about other effects that your respiratory problems (if you have it) may have on you. For each statement please select the box that applies to you these days:

- ○ True ○ False My cough or breathing is embarrassing in public
- ○ True ○ False My respiratory problems are a nuisance to my family, friends, and neighbors
- ○ True ○ False I get afraid or panic when I cannot get my breath
- ○ True ○ False I feel like I am not in control of my respiratory problems
- ○ True ○ False I have become frail or an invalid because of my respiratory problems
- ○ True ○ False Exercise is not safe for me
- ○ True ○ False Everything seems too much of an effort

12. These questions about how your activities might be affected by your respiratory problems. For each statement please select the box that applies to you because of your breathing:

- ○ True ○ False I take a long time to get washed or dressed
- ○ True ○ False I cannot take a bath or shower, or I take a long time to do it
- ○ True ○ False I walk slower than other people, or I stop to rest
- ○ True ○ False Jobs such as housework take a long time, or I have to stop to rest
- ○ True ○ False If I walk up one flight of stairs, I have to go slowly or stop
- ○ True ○ False If I hurry or walk fast, I have to stop or slow down
- ○ True ○ False My breathing make it difficult to do things such as walk up hills, carrying things up stairs, light gardening such as weeding, dance, bowl or play golf
- ○ True ○ False My breathing make it difficult to do things such as carry heavy loads, dig the garden or shovel snow, jog or walk briskly (5 miles per hour), play tennis or swim

13. We would like to know how your respiratory problems <u>usually</u> affect your daily life. For each statement please select the box that applies to you because of your respiratory problems:

- ○ True ○ False I cannot play sports or other physical activities
- ○ True ○ False I cannot go out for entertainment or recreation
- ○ True ○ False I cannot go out of the house to do the shopping
- ○ True ○ False I cannot do household chores
- ○ True ○ False I cannot move far from my bed or chair

14. How do your respiratory problems affect you? (Please select one)

- ○ **It does not stop me from doing anything I would like to do**
- ○ **It stops me from doing one or two things I would like to do**
- ○ **It stops me from doing most of the things I would like to do**
- ○ **It stops me from doing everything I would like to do**

SECTION 3 DYSPNEA-12 (D-12) Questionnaire

This questionnaire is designed to help us learn more about how your breathing is troubling you.

- Please read each statement and CLICK the box that best matches your breathing these days.
- If you do not experience what the statement describes, then tick the "none" box.
- Please respond to each of the 12 statements.

1. My breath does not go in all the way

- ○ **None**
- ○ **Mild**
- ○ **Moderate**
- ○ **Severe**

2. My breathing requires more work

- ○ **None**
- ○ **Mild**
- ○ **Moderate**
- ○ **Severe**

3. I feel short of breath

- ○ **None**
- ○ **Mild**
- ○ **Moderate**
- ○ **Severe**

4. I have difficulty catching my breath

- ○ **None**
- ○ **Mild**
- ○ **Moderate**
- ○ **Severe**

5. I cannot get enough air

- ○ **None**
- ○ **Mild**
- ○ **Moderate**
- ○ **Severe**

6. My breathing is uncomfortable

- ○ **None**
- ○ **Mild**
- ○ **Moderate**
- ○ **Severe**

7. My breathing is exhausting

- None
- Mild
- Moderate
- Severe

8. My breathing makes me feel depressed

- None
- Mild
- Moderate
- Severe

9. My breathing makes me feel miserable

- None
- Mild
- Moderate
- Severe

10. My breathing is distressing

- None
- Mild
- Moderate
- Severe

11. My breathing makes me agitated

- None
- Mild
- Moderate
- Severe

12. My breathing is irritating

- None
- Mild
- Moderate
- Severe

SECTION 4 EQ-5D-5L

Please check the ONE box that best describes your health TODAY.

Mobility

- I have no problems walking
- I have slight problems walking
- I have moderate problems walking
- I have severe problems walking
- I am unable to walk

Please check the ONE box that best describes your health TODAY.

Self-Care

- ○ I have no problems washing or dressing myself
- ○ I have slight problems washing or dressing myself
- ○ I have moderate problems washing or dressing myself
- ○ I have severe problems washing or dressing myself
- ○ I am unable to wash or dress myself

Please check the ONE box that best describes your health TODAY.

Usual Activities (e.g. work, study, housework, family, or leisure activities)

- ○ I have no problems doing my usual activities
- ○ I have slight problems doing my usual activities
- ○ I have moderate problems doing my usual activities
- ○ I have severe problems doing my usual activities
- ○ I am unable to do my usual activities

Please check the ONE box that best describes your health TODAY.

Pain/Discomfort

- ○ I have no pain or discomfort
- ○ I have slight pain or discomfort
- ○ I have moderate pain or discomfort
- ○ I have severe pain or discomfort
- ○ I extreame pain or discomfort

Please check the ONE box that best describes your health TODAY.

Anxiety/Depression

- ○ I am not anxious or depressed
- ○ I am slightly anxious or depressed
- ○ I am moderately anxious or depressed
- ○ I am severely anxious or depressed
- ○ I am extremely anxious or depressed

Thank you for your completing the questionnaires for the ECP study!

Please return the tablet to the research team!

Have a great day!

Save Submit