

## Multimedia Appendix 1

### MF/SS-CTCL QoL

Please complete these items regarding your experiences over the past 4 weeks.

**In the past 4 weeks...**

<b>Q1...how much did you worry that your mycosis fungoides or Sézary syndrome may get worse?</b>					
1	2	3	4	5	
Not at all	A little bit	Somewhat	Quite a bit	Very much	
<b>Q2. ...how often did you feel hopeless because of having mycosis fungoides or Sézary syndrome?</b>					
1	2	3	4	5	
Never	Rarely	Sometimes	Often	Always	
<b>Q3. ...how frustrated were you by the unpredictability of mycosis fungoides or Sézary syndrome?</b>					
1	2	3	4	5	
Not at all	A little bit	Somewhat	Quite a bit	Very much	
<b>Q4...how often did you feel depressed or sad because of mycosis fungoides or Sézary syndrome?</b>					
1	2	3	4	5	
Never	Rarely	Sometimes	Often	Always	
<b>Q5...how confident did you feel about managing your mycosis fungoides or Sézary syndrome?</b>					
1	2	3	4	5	
Absolutely confident	Very confident	Moderately confident	Mildly confident	Not at all confident	
<b>Q6. ...how severe were your mycosis fungoides or Sézary syndrome symptoms?</b>					<input type="checkbox"/>
1	2	3	4	5	Does not apply (I don't have symptoms right now)
Not at all	A little severe	Somewhat severe	Severe	Very severe	
<b>Q7. ... how burdensome was your mycosis fungoides or Sézary syndrome treatment?</b>					<input type="checkbox"/>
1	2	3	4	5	Does not apply (I don't have symptoms right now)
Not at all burdensome	A little burdensome	Somewhat burdensome	Burdensome	Very Burdensome	
<b>Q8. ...how much did your mycosis fungoides or Sézary syndrome limit your daily activities (work inside and outside of the house, self-care such as cooking, cleaning, getting dressed, etc.)?</b>					
1	2	3	4	5	
Not at all	A little bit	Somewhat	Quite a bit	Very much	

<b>Q9....how often did mycosis fungoides or Sézary syndrome (the condition or associated treatment) leave you too tired to work or do daily activities?</b>				
1	2	3	4	5
Never	Rarely	Sometimes	Often	Always
<b>Q10. ...how much did mycosis fungoides or Sézary syndrome negatively affect your relationships with others close to you?</b>				
1	2	3	4	5
Not at all	A little bit	Somewhat	Quite a bit	Very much
<b>Q11. ...how often did you feel that others do not understand what you are going through with mycosis fungoides or Sézary syndrome?</b>				
1	2	3	4	5
Never	Rarely	Sometimes	Often	Always
<b>Q12... to what extent did mycosis fungoides or Sézary syndrome make you feel uncomfortable being around people other than close family and friends?</b>				
1	2	3	4	5
Never	Rarely	Sometimes	Often	Always

The following items are not part of the MF/SS-CTCL QoL, but may provide useful information about the patient's experience:

**In the past 4 weeks...**

<b>...how much did mycosis fungoides or Sézary syndrome limit your ability to wear clothes you wanted to?</b>					
1	2	3	4	5	
Not at all	A little bit	Somewhat	Quite a bit	Very much	
<b>...to what extent were you able to cope with the daily demands (symptom impact and management, treatment, side effects, appointments, etc.) of mycosis fungoides or Sézary syndrome?</b>					
1	2	3	4	5	<input type="checkbox"/> Does not apply (I don't have symptoms right now)
Not at all	Very little	Somewhat	Quite a bit	To a great extent	

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