PBC Review

MRN sticker

Patient:

Signed: **Date:**

Clinical diagnosis: Year of diagnosis | Year of biopsy (or n/a)

Cholestatic LFTs | AMA/ANA (titre) | Histology

Treatment: Weight kg

1. Ursodeoxycholic Acid mg/day mg/kg/day

Was UDCA **discontinued** or was the **dose reduced**? (Circle, if applicable) DISCONTINUED REDUCED

Reason (e.g. not tolerated) and updated dose:

Response: (to be assessed following 1 year of UDCA treatment)

If ALP >1.67 ULN, has there been any decrease in ALP? (Circle yes or no) YES NO

Has ALP become <1.67 ULN ? YES NO

2. Obeticholic Acid mg/day

3. Fibrate mg/day

4. Other (specify)

Trial participation: YES NO If yes, which drug(s):

Symptom management:

Pruritus YES NO

Treatment:

Fatigue YES NO

Treatment:

Other *(Sicca, autonomic dysfunction, sleep difficulties)*:*

Treatment(s):

*May not apply to all patients. Sicca syndrome = dry/gritty eyes or mouth; Autonomic dysfunction = postural hypotension; Sleep difficulties may include daytime somnolence.

Updated by M Sivakumar (Imperial College, London).

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Bone density: Hip T-score: | Lumbar T-score:

Year of last scan:

Is the patient osteoporotic? YES NO

If osteoporotic, was appropriate treatment prescribed? YES NO

Details:

Date of last elastography: | Result:

Is this patient high risk?
Defined as bilirubin >50 µmol/L **OR** decreasing albumin **OR** signs of decompensation (variceal bleed, ascites or encephalopathy) YES NO

Details:

If yes, has transplant been considered? YES NO

Details:

Is this patient cirrhotic? YES NO

Date of last HCC screening: | Date of last OGD:

If co-existing Autoimmune Hepatitis, is there a record of diagnostic biopsy? YES NO

Year of biopsy:

Other concerns:

Other medications:

Follow up time: months

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PBC-10 QUESTONNAIRE (circle the appropriate answer for all questions 1-10)

IN THE LAST FOUR WEEKS, how often did you experience any of the following?						
1. I have felt embarrassed because of the itching	Never	Rarely	Sometimes	Most of the time	Always	Not applicable
2. If I eat or drink a small amount, I still feel bloated	Never	Rarely	Sometimes	Most of the time	Always	
3. My mouth was very dry	Never	Rarely	Sometimes	Most of the time	Always	
4. Fatigue interfered with my daily routine	Never	Rarely	Sometimes	Most of the time	Always	Not applicable
5. I had to force myself to do the things I needed to do	Never	Rarely	Sometimes	Most of the time	Always	
6. If I was busy one day, I needed at least another day to recover	Never	Rarely	Sometimes	Most of the time	Always	
7. Because of PBC, I found it difficult to concentrate on anything	Never	Rarely	Sometimes	Most of the time	Always	
Now some more general statements about how PBC may be affecting you as a person. How much does the following statement apply to you?						
8. I feel guilty that I can't do what I used to be able to do because of having PBC	Not at all	A little	Somewhat	Quite a bit	Very much	Not applicable
These statements relate to the possible effects of PBC on your social life and your life overall. Thinking of your own situation, how much do you agree or disagree with them?						
9. My social life has almost stopped	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	
10. PBC has reduced the quality of my life	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	

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