PATIENT CHECKLIST
Questions you should discuss with your doctor

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Undiagnosed or newly diagnosed patients have lots of questions. The IPPF has prepared this questionnaire to help you get the answers you need. We recommend you go through these questions before your doctor visit, and then share/discuss them with your doctor to help you find answers to questions you may not have known to ask. You may not need or be able to get answers for every question on the first visit.

**BASIC/INTRODUCTORY QUESTIONS**

Have you treated Pemphigus and Pemphigoid before?  
[ ] Yes  [ ] No  
If so, how often do you see a patient(s)?  

Is Pemphigus or Pemphigoid contagious?  
[ ] Yes  [ ] No  
(The answer is “NO” but it never hurts to hear it from your doctor)  
Please explain:  

Is Pemphigus or Pemphigoid inherited?  
[ ] Yes  [ ] No  
If there is a genetic connection, will my children get the disease?  
[ ] Yes  [ ] No  

**DIAGNOSIS**

Has an immune fluorescence test been done on the biopsy?  
[ ] Yes  [ ] No  
If not, will you order one?  
[ ] Yes  [ ] No  
Will you take a blood test to confirm the presence of antibodies?  
[ ] Yes  [ ] No  
What will you look for in an antibody test?  
(1) Antibodies to Desmoglein 1  
(2) Antibodies to Desmoglein 3  
(3) Other Antibodies  
When the antibody titer test is done, can you tell me the results?  
[ ] Yes  [ ] No  
How important is the titer count in treating the disease?
**INITIAL TREATMENT**

Will the first drug you prescribe for me be a steroid? [ ] Yes [ ] No

If yes, how many milligrams are you prescribing? _______________________

Why are you recommending that particular dosage?

____________________________________________________________________

____________________________________________________________________

When during the day should I take steroids? ______ Morning ______ Afternoon ______ Night

Should I take steroids with food? [ ] Yes [ ] No

Studies have shown steroids can cause serious side effects such as osteoporosis, thinning of the skin, loss of muscle tone, possible psychological problems, high blood pressure, stomach irritation, and high cholesterol. How can I cope with these side effects?

____________________________________________________________________

____________________________________________________________________

Since you are prescribing steroids, should I have a bone scan? [ ] Yes [ ] No

If yes, how often? ______________________

Steroids can cause stomach problems; should I take Pepcid, Zantac, or Tagament? [ ] Yes [ ] No

If I am on steroids **only**, how often should I have a blood test? ______________________

What should we look for in a blood test?

____________________________________________________________________

____________________________________________________________________

Will you also prescribe any of the following?

[ ] Imuran [ ] CellCept [ ] Cytoxan [ ] Dapsone [ ] Plaquenil

[ ] a cycline drug [ ] niacinamide [ ] other ______________________

How many mg will you prescribe? ________ And how often? ______________________

What are the side effects of these drugs?
If I am on immunosuppressive drugs, how often should I have a blood test?

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

What should we look for in a blood test?

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

If the blood test shows a problem, can I reduce my drug instead of going off of it completely? Or, is there something else I should do?

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
SPECIALIST AND DIETARY HEALTH QUESTIONS

Should I see an Internist or other physician to help me deal with drug side effects? [ ] Yes [ ] No  
Who do you recommend? ____________________________  

Certain blood pressure medicines can trigger Pemphigus flare ups. If I need this kind of medication which ones should I avoid?  
_________________________________________________  

Are there any foods I should stay away from or avoid?  
_________________________________________________  

Do you recommend a specific diet?  
_________________________________________________  

Can I go out in the sun? [ ] Yes, [ ] No  
Should I exercise, and if so how much should I do, and how often? [ ] Yes, [ ] No  
_________________________________________________  

Should I consult with an Ophthalmologist? [ ] Yes, [ ] No  
Who do you recommend? ____________________________  

Is stress an important factor? ____________________________  

Are there any vitamins or supplements I should take? [ ] Yes, [ ] No  
Which ones should I avoid? ____________________________  

Should I take Calcium supplements? [ ] Yes [ ] No  
Vitamin D? [ ] Yes [ ] No  

Can I take immune enhancing drugs? [ ] Yes, [ ] No
The IPPF suggests you keep a diary tracking the course of your disease. This should include the dates of any adverse reactions to medication, your diet, any physical problems you are experiencing, and pictures if possible. This can be useful in planning your course of treatment and sharing your progress/flare ups with your doctors. Learning to live with Pemphigus and Pemphigoid is a process and it takes time and patience. Please feel free to call us, or you may want to consult a counselor or a therapist.

**STEROID TREATMENT**

Will I be able to taper off of steroids?  [ ] Yes [ ] No

If Yes, when ___________________________ and by how much? _____ mg

Should I expect to have inflammation or a flare when tapering?  [ ] Yes [ ] No

What do you recommend if I find that the inflammation is too much to manage?

________________________________________________________________________
________________________________________________________________________

Can you prescribe the steroids in a smaller mg pill so I can taper slower?

________________________________________________________________________
________________________________________________________________________

Should I be using topical steroids along with the systemic steroids?  [ ] Yes [ ] No

**OTHER TREATMENT**

You are prescribing ______________________ and my initial dose is _____ mg,

Will you be increasing it later?  [ ] Yes [ ] No

If Yes, when ___________________________ and by how much? _____

________________________________________________________________________ Mg

How long does it take for this medication to begin working? _______________

What side effects should I expect? _______________________________________

If my condition has not improved by then will you recommend a different medication? If so, which one and at what dosage? ______________, ______ mg

What side effects should I expect from this new medication? _______________
How long does it take for this medication to begin working? ________________
ORAL DISEASE QUESTIONS
Since I have oral activity should I see a Dentist? [ ] Yes [ ] No
Do you know one with experience that you would recommend?

Are there any types of dental procedures that I should avoid? [ ] Yes [ ] No

Should I be avoiding or using specific dental/oral products? [ ] Yes [ ] No

Would you recommend topical oral steroids? [ ] Yes [ ] No

How long does it take for this type of medication to begin working?

Please tell your physician about the IPPF.

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Notes from your Doctor Visit

This page is for note taking during your visit with your doctor. There is also a short self-evaluation to identify areas in your lifestyle that may assist you in self-managing your condition.

Doctor’s Name __________________________ Assistant’s Name _______________

Date of Visit __________________ Phone ___________ Email __________________

Treatment Plan:

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

My Health Goal(s):

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

State of Mind - My greatest causes of stress and anxiety are:

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

I feel most comfortable and/or peaceful when I engage in my favorite pastime or passion. They are:

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________