

## Questions for your ECP

Make sure your appointment with your ECP meets your needs.

### **About My Disease or Disorder:**

- What is my diagnosis?
- What caused my condition?
- Can my condition be treated?
- How will this condition affect my vision now and in the future?
- Should I watch for any particular symptoms and notify you if they occur?
- Should I make any lifestyle changes?
- Is my condition hereditary? What should I tell my family members?

### **About My Treatment:**

- What is the treatment for my condition?
- When will the treatment start, and how long will it last?
- What are the benefits of this treatment, and how successful is it?
- What are the risks and side effects associated with this treatment?
- Are there foods, drugs, or activities I should avoid while I'm on this treatment?
- If my treatment includes taking a medication, what should I do if I miss a dose?
- Are other treatments available?
- Are there new treatments being developed? Should I consider taking part in a clinical trial?

### **About My Tests:**

- What kinds of tests will I have? Will genetic testing be included?
- What do you expect to find out from these tests?
- When will I know the results?
- Do I have to do anything special to prepare for any of the tests?
- Do these tests have any side effects or risks?
- Will I need more tests later?

### **A few more tips:**

- If you don't understand an answer, ask questions until you do understand.
- Take notes, or get a friend or family member to take notes for you, or bring a tape-recorder to assist in your recollection of the discussion.
- Ask your ECP to write down his or her instructions to you.



Seeking A Cure For  
Retinitis Pigmentosa, Macular Degeneration,  
Usher Syndrome and Allied Retinal Dystrophies

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- Ask your ECP for printed material about your condition.
- If you still have trouble understanding your ECP's answers, ask where you can go for more information.
- Other members of your health care team, such as nurses and pharmacists, can be good sources of information. Talk to them, too.
- Other organisations, such as local patient organisations and support groups can help too.