



HearUsYARR.org

Provider

Date

Preparation

- ☐ Healthcare records checklist
- ☐ Health insurance card
- ☐ Office, hospital system, state, or local policies
- ☐ Scientific papers
- ☐ Other:

Prepare for Your Medical Appointment

Write a 30-second pitch of
your rare disease(s).

What are 1-3 goals
you want to
accomplish by the end
of this appointment?

What are your main recent symptoms?

Do you have any medical updates to share,
such as new diagnoses or hospitalizations?



Preparing Your Questions

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Sample Questions

Provider-Patient Relationship

- "How do you like to communicate with patients?"
- "When treating new patients, is your typical approach more holistic or do you like to just tackle one symptom at a time?"
- "Do you have experience with rare disease patients?"
- "Have you ever treated someone with my condition? If not, are you open to reviewing some information that I send you?"
- "Are you open to discussing my treatment with some of my previous providers or other specialists?"

New Treatment Options

- "What side effects can I expect from this new treatment?"
- "Will this treatment interact with any medications I am taking?"
- "Are there any over-the-counter medications or supplements I should take, or ones I should avoid taking?"
- "Are there any new clinical trials I should consider? If so, where can I find more information about the risks and potential benefits?"

After-Appointment Planning

- "Is there anything else you recommend treatment-wise before my next appointment?"
- "When would you recommend another appointment?"
- "Do you recommend other resources or support groups?"

Your Questions

