WHAT IS TELEHEALTH?
Telehealth is generally described as a virtual communication, such as a phone or video visit, used to deliver care outside of a typical or traditional health care facility. During the COVID-19 pandemic, “social distancing” is critical to minimize the spread of the coronavirus. Since many rare disease patients need to receive ongoing care, telehealth is increasingly being used as an alternative to in-person health care. If you are interested in telehealth, check with your individual provider and insurer to see if it is available to you.

HOW TO PREPARE FOR YOUR TELEHEALTH APPOINTMENT

*Find the right spot*
> It is important that you find a spot that allows for an uninterrupted appointment. Find a location that is:
  - Private
  - Quiet
  - Well-lit
  - Has a strong WiFi signal

*Download the appropriate app/software before your appointment*
> Different providers use various applications for telehealth. Ensure that you have downloaded the correct application for your appointment.
> Clarify with your provider if it will be a video or audio-only appointment.

*Test the audio/video*
> Test the technology with a buddy. It may be possible for someone from your provider’s office to test it with you.
> This is a new process for many of us. We are all learning and need to practice. Flexibility is key!

1 Source: who.int/sustainable-development/health-sector/strategies/telehealth/en/
Have your questions prepared in advance

> Treat this like any other appointment. Take a few minutes in advance to jot down what you would like to go over. Come prepared with your questions and concerns.

Create a backup plan if your technology fails

> Be prepared to call your provider if you have difficulty with video conferencing at the time of your appointment.

**THINGS TO CONSIDER**

**Be sure to collect any items you would bring to an in-person appointment.**

> This could be devices, medications, or medical documents.

> You may be asked to take photos (such as photos of skin, hands, feet) and email them to your provider through secure email. You have the right to ask your provider with whom these photos will be shared with and how they will be stored.

**If a loved one typically joins you for your appointments, have them participate in the virtual appointment as well.**

> Some providers may allow another person in a different location to join the virtual visit.

**If possible, ask a tech-savvy loved one to be nearby or on call to help if you run into technical difficulties.**

**Set your expectations.**

> This will be similar to your typical appointments, but some things may be different.

> Know what your state and provider allows via telehealth.

> Telehealth enables you to discuss with your provider exactly what follow-up is needed, and whether future appointments might include an in-person visit. Necessary testing and genetic evaluation can be coordinated through telehealth visits.

**ADDITIONAL RESOURCES**

Learn about your state's telehealth policies and regulations here: cchcpca.org/resources/covid-19-related-state-actions

Alliance for Connected Care
connectwithcare.org

**COVID-19 EDUCATION SUPPORT**

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