Participant

**Linkt Health** Datacubed Health **Username:** [site email+ID]

**Linkt Health Temp Password:** [insert temp pass]

**Linkt Health Password:**[insert permanent pass]

Study Partner

**Linkt Health** Datacubed Health **Username:** [site email+ID]

**Linkt Health Temp Password:** [insert temp pass]

**Linkt Health Password:** [insert permanent pass]

**ALLFTD Phone Application**  
ALLFTD Study Partner Take-Home Instructions and Information

Thank you for agreeing to use the ALLFTD Phone App. We are studying this App to investigate the potential benefit that modern technologies may have for advancing our knowledge of frontotemporal lobar degeneration (FTLD). We are using a cell phone app to learn more about those who have FTLD or may be at risk of developing FTLD. Specifically, we are planning to do this by having ALLFTD participants complete surveys, play memory and thinking games, and complete some speaking and motor tasks. As a Study Partner of one of the ALLFTD participants, we will ask you to complete some surveys and to assist with some motor tasks (like a walking task).

We think that having you and your loved one complete these tasks using the App will help us better monitor changes in their daily functioning, and also limit your burden by not having to travel to the clinic more frequently. We anticipate that the ALLFTD participant will complete all of the App tasks in a location of their choosing, aka not the clinic! We ask that you help ensure that wherever they choose to complete these tasks is **free from noise or distractions.** You will also have a few surveys to complete through your version of the app.

**What will I need to do to complete my App participation?**

To complete your App participation, you will need to complete your prompted tasks on Linkt (the name of the cell phone App). Your ALLFTD participant will be asked to complete three separate sets of tasks over about two weeks. For more information on what your ALLFTD participant will be asked to do, please consult their Take Home Information Sheet. We anticipate that as a Study Partner, your task requests will be quite limited, and will likely consist of completing a survey or two every six months. We would, however, like you to provide assistance to your ALLFTD participant for app navigation and motor tasks as needed.   
  
Reminders:   
At the top of your app’s home page, you will see a countdown of the number of days and hours until the next chapter begins.

You will receive an in-app message in Isabella’s Inbox with the following reminders:

* On or near the date of tasks arriving for the ALLFTD Participant (your study partner)

You will also receive a banner notification when:

* A new task arrives for *you* to complete
* The beginning of a new chapter
* The arrival of an in-app message
* 24 hours since previous passive data upload

During each chapter, you will be prompted to complete a few surveys. In your first chapter, you will be asked to complete two surveys, including “Technology Familiarity Survey” and “Study Partner Experience Survey.” Not every chapter is identical, but you ***may*** be asked to complete:

1. Technology Familiarity Survey
2. COVID-19 Survey
3. Study Partner Experience Survey
4. Corticobasal Functional Scale
5. Revised Self-Monitoring Scale
6. Zarit Burden Inventory

**How can I help the ALLFTD participant?**

Setting up the Environment

Because the participant will be completing the task in their home, without direct oversight of study staff, we ask that you help us collect the highest quality data possible. There are a few things you can do to set up the best environment for testing. First, you can help ensure that the participant is taking the tests in a room that is free of distractions, such as televisions, pets, or children. Because we are recording audio files, it is very important that background noises, such as fans, televisions, or family members, are limited to the extent possible. If the participant is having difficulty logging onto the App, you can help.

Navigating the App

You can also be available to help the ALLFTD participant navigate the App, but it is important that you do not help them take the tests; you can remind them to guess if they are unsure. We recommend that you are close enough that the participant can reach out to you for help, but suggest that you are not in the same room unless necessary, as your presence could be distracting.   
  
Helpful navigation information:

* The tasks are found in the numbered bubble on the home page of the app.
* Your messages will arrive in Isabella’s Inbox in the top left corner of the app’s home page.
* The treasure box at the top of the app’s home page will tell you the number of tasks completed (this will be different for your partner, the primary participant).

Walking Task Assistance

The Walking Task, in particular, is one that we expect might require assistance from you. If this is the case we’d like you to help choose an ideal path for your ALLFTD participant to walk. The ideal path allows the participant to walk in a straight line, on a flat surface (i.e., does not include stairs), in the home. When choosing this path be sure to make sure that there isn’t anything your participant could walk into, trip on, or experience that may not be safe for them. Your participant will not necessarily be asked to complete this task, or may only be asked to complete it a few times.

Payments

You will not be paid for your use of the ALLFTD Mobile App. However, you can help [primary participant] locate their in-app payments. Once [primary participant] has completed the tasks assigned to them in each, as outlined in their Participant Take Home Information, an Amazon e-gift card will be available via the in-App messages.

**Questions?**

A coordinator will reach out to you and the ALLFTD participant approximately two weeks prior to their next App-visit timing window. We hope that you and your ALLFTD participant will continue to participate in the ALLFTD App for the duration of the ALLFTD study. We believe that this technology is very promising, and your participation will help us answer important questions!