

## Chapter 5

### Appointment Documents and Forms

**This chapter outlines the appointment documents and forms needed for the pre-visit planning.**

LLFS assessments can be conducted in the participants' homes or in the Field Center's clinic space. Although most visits are conducted in the participant's home, a map and directions to the specific field center will be provided whenever the participant opts to an in-clinic visit.

For returning participants, we will send a cover letter discussing our plans for a second in-home visit, inquiring about their interest in continued participation (see *Appendix 1a*). This cover letter will also contain a new consent form for the participant to read and sign. LLFS staff will follow-up these mailings with a telephone call in 2-4 weeks. For potential new participants, we will send a cover letter (*Appendix 1b*) discussing the study, how we identified them (through other family members participating in LLFS), and a reply card (*Appendix 1c*) to indicate their willingness to participate. If they are interested, as indicated in their returned reply card, we will call to follow-up with them. If we do not receive the reply card, we will call them in a few weeks to see if they are interested in participating. Additionally, the study has developed a form for all visits that serves as both a visit reminder and instructional document. This form will help ensure that each participant receives a document specifying the date and time of his/her visit along with specific instructions to prepare for the visit. The form, developed for this purpose, is located in the Appendix.

Once a subject has agreed to participate in a second visit, an appointment will be made for each individual to be seen either at the participant's home or at the clinic. Additionally, some families will prefer to be seen together in one location while others will prefer to be seen at separate locations. The study staff will take into consideration the size of the home and number of participants seen to ensure there is sufficient space to see any family who wants to be seen in one home. They will also be as flexible as possible in order to accommodate each participant's reasonable preferences for time, day and location of the visit. Weekend and evening visits may be requested and granted at the discretion of each Field Center's PI and his/her staff.

After the LLFS appointment is made, the instructional letter (please refer to *Ch. 5: Appendix 2a-d*) is sent to each scheduled participant several days before the visit. The purpose of this letter is to remind the participant of the date/time/location of the visit as well as to provide all necessary instructions regarding the visit.

First, the participant's name will be inserted at the top of the page on the line provided. Next, the day of the week, date of the appointment and time will be jotted down on the lines provided. Some questionnaires that can be self-administered will also be sent with this information. The participant should complete these before their appointment and the field personnel will collect them during the in-person visit, checking for completeness before leaving the home.

The specifics for the visit are then outlined for each participant so that s/he will be made aware of the preparations that need to be made for the visit.

First, the participants are asked to fast for at least 8 hours prior to the visit and no more than 16 hours. Participants with diabetes should limit fasting to 12 hours. Visits should be scheduled to accommodate these fasting limits or if not possible, venipunctures should be arranged through a local lab. Participants are encouraged to drink water beforehand but asked to take nothing else aside from their medications.

Next, new participants and existing participants without a validated age are asked to have available a copy of the documentation used to verify their age, such as a birth certificate, passport, military record, marriage license.

The participants are asked to have available all medication containers for medications that they have taken in the past two weeks available for the examiner. It is stated that this includes both prescription and over-the-counter medications including vitamins, cold or allergy medications, aspirin, eye drops, nicotine (gum and e-cigarettes), creams and salves, and any other medications.

Participants are encouraged to take any medications that they normally take. These include pills, dermal patches, eye drops, creams, salves, and injections (including insulin).

It is suggested the participants wear loose, comfortable clothing and shoes or have a pair of shorts available. This will help the examiners conduct the more physical assessments.

Next, participants are reminded to have their eyeglasses available if they need them to read. If they have a hearing aid, they are reminded to wear it for the visit.

Additionally, they are reminded to have a cane or walker available during the visit if they use any of these devices.

A phone call to the participant will be made either a day before the visit or the morning of as a reminder and to address any questions.

Samples of various Instruction Forms and Letters that are being utilized by some of the LLFS Field Centers are included in Appendices 1-7 to this Chapter.

## Chapter 5: Appendix 1a



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Columbia University  
University of Pittsburgh  
University of Southern Denmark  
Washington University School of Medicine

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### **Cover Letter for Existing Participants**

[Date]

Dear [name],

Greetings from all of us at the Long Life Family Study. First of all, we want to thank you for your and your family's participation in the LLFS. With your help, the Study continues to make inroads into a better understanding of how longevity and healthy aging can run in families. If you haven't already, please see our most recent newsletter for updates from the Study.

As you might have read in the newsletter, in this next phase of the Study, we would like to come to you to perform another in-person evaluation. You may recall that we performed such a home visit with you sometime between 2006 and 2009. Participating in a second in-person evaluation with us is particularly important for the Study because we then have the opportunity to perform some very important measures and to see if anything has changed since we last saw you. Of course it is also wonderful for us that we can visit with you in person!

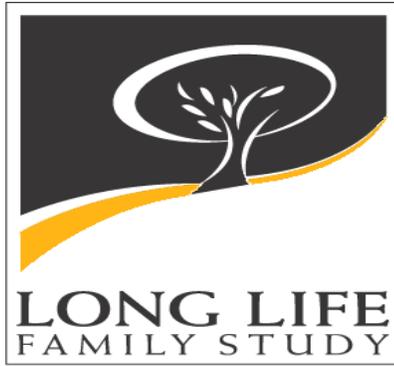
In this visit we will perform a few new measures, while there will be others we don't have to repeat. Because of these changes and because we want to be sure you know what to expect in our visit with you, we have enclosed a slightly revised study consent form. The consent form describes what will happen in this next phase of the Long Life Family Study, including both the home visit and the annual follow-up phone calls and questionnaires. Please read the consent form and see if you have any questions or concerns. We will be calling you about 2-4 weeks before we would like to come visit you, at which time we will describe the study in more detail and answer any questions you might have. Of course, if you want to reach us, please call us at (888) 333-6327 (toll free) or (617) 638-6679.

Again, with our heart-felt appreciation for your participation in the Long Life Family Study,

Our Fond Regards,

Long Life Family Study Research Team

## Chapter 5: Appendix 1b



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### **Cover Letter for New Participants**

[Date]

Dear [name],

Members of your family are enrolled in the National Institutes of Health's Long Life Family Study. As you may have heard from one of them, your relatives are enrolled in the Study because of how strongly longevity appears to run in your family. We are writing you with the fervent hope that you will consider also being a participant in the Study.

To briefly let you know what is involved, we come visit you to collect some data and a blood sample. We ask questions to test your memory and other functions of how well your mind is working and then we perform some tests, if you are able, of your strength, balance and walking ability. We perform two harmless and painless tests that check how big of a breath you can take and using sound waves, how well blood flows in the arteries in your neck. We also ask questions about your medical history, health-related habits and other factors that could be related to the longevity in your family. After the home visit, we check in with you each year to collect some information over the phone and by mail.

We have enclosed a recent newsletter that provides you with some updates from the Study with the hopes that you can get an idea of the research we are performing and our recent discoveries and findings. The participants indicate how much they love these newsletters and the information that shows just how special families like yours are.

We very much hope that you are interested in participating in the Long Life Family Study. We have enclosed a response card along with a postage-paid addressed envelope. Can you please provide your response and place it in the mail for us? If indeed you are interested, we will follow-up with you by telephone. We hope that you don't mind that if we don't hear from you within a few weeks we will call you to see if you are interested in being a study participant.

If you would like to call us with any questions, our phone numbers are (888) 333-6327 (toll free) or (617) 638-6679.

Thank you so much for your time and consideration.

With Our Fond Regards,

Long Life Family Study Research Team

### Chapter 5: Appendix 1c



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### New Participant Reply Form

### REPLY FORM – The LONG LIFE Family Study

Yes, I am interested. Please contact me with more information!

Name: \_\_\_\_\_

Address: \_\_\_\_\_

City: \_\_\_\_\_ State: \_\_\_\_\_ Zip: \_\_\_\_\_

Phone # (        ) \_\_\_\_\_ Date of Birth: \_\_\_\_ / \_\_\_\_ / \_\_\_\_

Best day and time to call me: \_\_\_\_\_

## Chapter 5: Appendix 2a



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### **Instructions for Long Life Family Study Visit (Sample Form – Visit Instructions for Visit 2 – Current Enrollees)**

Dear \_\_\_\_\_:

Your Long Life Family Study In Person visit is scheduled for:

\_\_\_\_\_ / \_\_\_\_\_ / \_\_\_\_\_ at \_\_\_\_\_:\_\_\_\_\_ AM/PM  
Day of Week      Month      Date      Year      Time

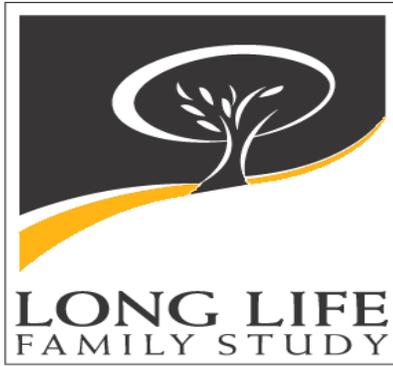
**Please be sure to review these instructions for your upcoming visit since they are very important for your visit's success. This visit will take approximately 3-4 hours.**

**In preparation for your visit, please complete the enclosed questionnaires by yourself, without the help of another person. The LLFS Research Team will review these questionnaires for completeness during your in person visit.**

- Please **FAST** (take nothing by mouth except water and medications) for at least 8 hours prior to your appointment and **drink plenty of water before your visit.**
- On the day of your visit, please take any medications as prescribed. These include pills, dermal patches, eye drops, creams, salves, and injections (including insulin).
- Have all containers for prescription and over-the-counter medications that you have taken in the past two weeks available. This includes vitamins, cold or allergy medications, aspirin, eye drops, creams and salves, and any other medications.
- Please wear loose, comfortable clothing (or have a pair of shorts available) and wear shoes that are suitable for walking.
- Have your eyeglasses available for reading, if needed. If you have a hearing aid, please wear it.
- If you use aids to get around, such as a cane or walker, please be sure to have them available during your visit.

If you have any questions or concerns with this scheduled visit, **please call us toll-free at [XXX-XXX-XXXX].** We look forward to seeing you!

## Chapter 5: Appendix 2a



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### **Instructions for Long Life Family Study Visit (Sample Form – Visit Instructions for Proxy Visits)**

Dear \_\_\_\_\_:

The Long Life Family Study In Person visit for \_\_\_\_\_ is scheduled for:

\_\_\_\_\_ / \_\_\_\_\_ / \_\_\_\_\_ at \_\_\_\_\_:\_\_\_\_\_ AM/PM  
Day of Week      Month      Date      Year      Time

**Please be sure to review these instructions for your family member's upcoming visit since they are very important for the visit's success. This visit will take approximately 3-4 hours.**

**In preparation for this visit, please complete the enclosed questionnaires on behalf of your family member participating in the Long Life Family Study. The LLFS Research Team will review these questionnaires for completeness during this in person visit.**

- Please have your family member **FAST** (take nothing by mouth except water and medications) for at least 8 hours prior to this appointment. Have them **drink plenty of water before the visit.**
- On the day of their visit, please have them take any medications as prescribed. These include pills, dermal patches, eye drops, creams, salves, and injections (including insulin).
- Have all containers for prescription and over-the-counter medications that you have taken in the past two weeks available. This includes vitamins, cold or allergy medications, aspirin, eye drops, creams and salves, and any other medications.
- Please have your family member wear loose, comfortable clothing (or have a pair of shorts available) and wear shoes that are suitable for walking.
- Have their eyeglasses available for reading, if needed. If they wear a hearing aid, please wear it.
- If your family member uses aids to get around, such as a cane or walker, please be sure to have them available during this visit.

If you have any questions or concerns with this scheduled visit, **please call us toll-free at [XXX-XXX-XXXX].** We look forward to seeing you!

## Chapter 5: Appendix 2a



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### **Instructions for Long Life Family Study Visit (Sample Form –Visit Instructions for New Enrollees)**

Dear \_\_\_\_\_:

Your Long Life Family Study In Person visit is scheduled for:

\_\_\_\_\_ / \_\_\_\_\_ / \_\_\_\_\_ at \_\_\_\_\_:\_\_\_\_\_ AM/PM  
Day of Week      Month      Date      Year      Time

**Please be sure to review these instructions for your upcoming visit since they are very important for your visit's success. This visit will take approximately 3-4 hours.**

**In preparation for your visit, please complete the enclosed questionnaires by yourself, without the help of another person. The LLFS Research Team will review these questionnaires for completeness during your in person visit.**

- Please **FAST** (take nothing by mouth except water and medications) for at least 8 hours prior to your appointment and **drink plenty of water before your visit**.
- Please have available a copy of the documentation that you use to verify your age, such as a birth certificate, passport, military record, marriage license. We will need to see it at your visit.
- On the day of your visit, please take any medications as prescribed. These include pills, dermal patches, eye drops, creams, salves, and injections (including insulin).
- Have all containers for prescription and over-the-counter medications that you have taken in the past two weeks available. This includes vitamins, cold or allergy medications, aspirin, eye drops, creams and salves, and any other medications.
- Please wear loose, comfortable clothing (or have a pair of shorts available) and wear shoes that are suitable for walking.
- Have your eyeglasses available for reading, if needed. If you have a hearing aid, please wear it.
- If you use aids to get around, such as a cane or walker, please be sure to have them available during your visit.

If you have any questions or concerns with this scheduled visit, **please call us toll-free at [XXX-XXX-XXXX]**. We look forward to seeing you!

### Chapter 5 – Appendix 3



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### Instructions for Long Life Family Study Visit (Sample Form – Remote Phlebotomy Service Instructions)

Date: \_\_\_\_\_

Phlebotomy Service Address

Attn: Insert Name

Address

City, State Zip

Re: (Insert Participant Name)'s Blood Draw for the Long Life Family Study

Dear \_\_\_\_\_:

Thank you for your assistance in completing the venipuncture portion of the Long Life Family Study (LLFS). \_\_\_\_\_ is **planning on coming to your facility on Insert Date.** Enclosed are the following materials that you will need to complete the blood draw:

- 9 All tubes and shipping materials, including an extra set of collection tubes if needed
- 9 Detailed instructions for collecting the LLFS specimen
- 9 Detailed instructions for shipping the LLFS specimen, including Saturday delivery stickers if applicable
- 9 A signed copy of the consent form
- 9 The Blood Collection Form

**Insert billing information.** If you have any questions regarding this, I may be reached at **[insert E-Mail address and telephone number]**. Thank you again for your assistance.

Sincerely,

\_\_\_\_\_

## Chapter 5 – Appendix 4



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### **Instructions for Long Life Family Study Visit (Sample Form – Phlebotomy Information Form)**

Is there a hospital lab, outpatient lab or a doctor's office that you prefer to have draw your blood?

- Yes  
 No

If "No", we will identify a facility convenient to you and make the arrangements to draw your blood at no cost to you or your insurance company.

If yes, please note the following the information:

Dr. or Facility Name: \_\_\_\_\_

Address: \_\_\_\_\_

Telephone Number: \_\_\_\_\_

We will make arrangements with the facility to draw your blood at no cost to you or your insurance company.

## Chapter 5 – Appendix 5



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### **Instructions for Long Life Family Study Visit (Sample Form – Telephone Interview Consent, age validated)**

Date: \_\_\_\_\_

Dear \_\_\_\_\_:

Thank you for agreeing to participate in the Long Life Family Study (LLFS). LLFS is an international project that is studying families who have several members who have reached very old age. With your help, we are hoping to learn why some people live until a very old age and why some families maintain their health far longer than the average family. By helping us understand longevity, you can help to improve the health of future generations.

It has been at least 3 years since you and your family members were first examined for this study. We have been keeping up with you by phone or mail and have been tabulating the changes in your health over time. The repeat examination that we have proposed will include physical measurements such as blood pressure, strength, walking, and cholesterol and glucose levels along with interview questions on your health, energy level, sleep and physical activity.

Enclosed is a copy of the consent form for this second visit. Please read it carefully and if you have questions, please call \_\_\_\_\_ at \_\_\_\_\_. Once your questions have been answered, initial the bottom of each page, check the boxes on pages \_\_\_\_\_ and sign your complete signature on the last page. Please also complete the **Contact Information Sheet and the Phlebotomy Information Form**. Return these forms along with your **signed consent form** in the addressed-stamped envelope provided, within 5 days of receiving this letter.

After we receive your signed consent form, we will call you to schedule an interview. This interview will take about 30 minutes. We will ask you questions related to your current and past medical history, daily living activities, health habits, physical activity, your ability to process and recall information and your current medications. **Please gather all of your current medications, both prescription and over-the-counter that you have taken in the last 2 weeks and have them available during our telephone visit.**

During this interview we will also discuss arrangements to complete a blood draw if you are willing.

If you have any questions, please call \_\_\_\_\_ at \_\_\_\_\_. Thank you again for your assistance in this important research project. We look forward to talking with you.

Sincerely,

Long Life Family Study Staff

## Chapter 5 – Appendix 5a



### ***A Collaborative Study, Including:***

Boston University Medical Center  
Columbia University  
University of Pittsburgh  
University of Southern Denmark  
Washington University School of Medicine

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### **Instructions for Long Life Family Study Visit (Sample Form – Telephone Interview Consent, age unvalidated)**

Date: \_\_\_\_\_

Dear \_\_\_\_\_:

Thank you for agreeing to participate in the Long Life Family Study (LLFS). LLFS is an international project that is studying families who have several members who have reached very old age. With your help, we are hoping to learn why some people live until a very old age and why some families maintain their health far longer than the average family. By helping us understand longevity, you can help to improve the health of future generations.

It has been at least 3 years since you and your family members were first examined for this study. We have been keeping up with you by phone or mail and have been tabulating the changes in your health over time. The repeat examination that we have proposed will include physical measurements such as blood pressure, strength, walking, and cholesterol and glucose levels along with interview questions on your health, energy level, sleep and physical activity.

Enclosed is a copy of the consent form for this second visit. Please read it carefully and if you have questions, please call \_\_\_\_\_ at \_\_\_\_\_. Once your questions have been answered, initial the bottom of each page, check the boxes on pages \_\_\_\_\_ and sign your complete signature on the last page. Please also complete the **Contact Information Sheet and the Phlebotomy Information Form**. Return these forms along with your **signed consent form and a copy of the verification of your birth date** in the addressed-stamped envelope provided, within 5 days of receiving this letter.

After we receive your signed consent form, we will call you to schedule an interview. This interview will take about 30 minutes. We will ask you questions related to your current and past medical history, daily living activities, health habits, physical activity, your ability to process and recall information and your current medications. **Please gather all of your current medications, both prescription and over-the-counter that you have taken in the last 2 weeks and have them available during our telephone visit.**

During this interview we will also discuss arrangements to complete a blood draw if you are willing.

If you have any questions, please call \_\_\_\_\_ at \_\_\_\_\_. Thank you again for your assistance in this important research project. We look forward to talking with you.

Sincerely,

Long Life Family Study Staff

## Chapter 5 – Appendix 6



### ***A Collaborative Study, Including:***

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Washington University School of Medicine

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### **Instructions for Long Life Family Study Visit (Sample Form – Telephone Return Packet Letter)**

Date: \_\_\_\_\_

Dear \_\_\_\_\_:

Thank you for agreeing to be a part of the Long Life Family Study (LLFS). LLFS is an international project that is studying families who have several members who have reached very old age. With your help, we are hoping to learn why some people live until a very old age and why some families maintain their health far longer than the average family. By helping us understand longevity, you can help to improve the health of future generations.

It has been at least 3 years since you and your family members were first examined for this study. We have been keeping up with you by phone or mail and have been tabulating the changes in your health over time. The repeat examination that we have proposed will include physical measurements such as blood pressure, strength, walking, and cholesterol and glucose levels along with interview questions on your health, energy level, sleep and physical activity.

Recently we mailed you a packet of information that we asked you to complete and return. To date, we have not received this information. If you did not receive the packet or need another one to be sent, please contact us. We would appreciate hearing from you. If you have changed your mind about being a part of the Long Life Family Study please let us know.

If you have any questions or concerns, please contact \_\_\_\_\_ at \_\_\_\_\_ or at \_\_\_\_\_. We look forward to hearing from you. Together we can discover the secrets of a long and healthy life.

Sincerely,

Long Life Family Study

## Chapter 5 – Appendix 7



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### **Instructions for Long Life Family Study Visit (Sample Form – 'Unable to Contact You' Letter)**

Date: \_\_\_\_\_

Dear \_\_\_\_\_:

A while ago you agreed to participate in the second in-person visit for the Long Life Family Study (LLFS). To date, I have not been successful in reaching you. If you are still interested in being part of this important international study of longevity I can be reached at (insert staff e-mail and phone number). For your convenience our toll free number is 1-888-333-6327. To refresh your memory, I have enclosed information about the study or you can visit our website at [www.longlifefamilystudy.org](http://www.longlifefamilystudy.org). If you have changed your mind about being a continuing part of LLFS it is important for us to know this as well. If we do not hear from you, I will plan to contact you in two weeks. Please keep in mind that we will be continuing to schedule appointments over the next few months.

If you have any questions or concerns, please feel free to contact \_\_\_\_\_ at \_\_\_\_\_ or at \_\_\_\_\_. I look forward to hearing from you. Together we can discover the secrets of a long and healthy life.

Sincerely,

(Insert staff name)

Long Life Family Study