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This is an update on the progress of the LifeGene project. It is the second of a continuing series of regular newsletters from LifeGene so that we can keep you informed on how things are progressing. If you have any comments regarding the form of the newsletter or if you have any other questions, please do not hesitate to contact us!

News

The winter and spring of 2009 have been very eventful for LifeGene! We have received approval from the ethics board for the pilot study and have been busy planning and preparing for the pilot study with 5,000 participants beginning in the fall of 2009. As a first step, a small "pre-pilot" study with about 100 participants was conducted in April and May in order to make sure that the pilot study will run smoothly when it is commenced. A prototype of the coming Test Center has been built at the Karolinska Institute in order to test the design and logistics as well as the ambiance of the Test Center.

Planning and preparing for the pilot-study has involved decisions on what physical tests, as well as biological samples such as blood and urine, the participants of LifeGene will complete. Considerable effort has also been devoted to finalizing the questionnaire. An important part has been the development of redesigned questionnaires for physical activity and diet. Both these are currently being tested and validated.

Finalizing the Questionnaire

Mikael Eriksson has been responsible for the questionnaire that each participant will complete with data about lifestyle, previous or current medication, health history and such. A number of expert groups, both Swedish and international, from various research fields such as cardiovascular diseases, musculo-skeletal diseases and psychiatry have held workshops and presented lists of what questions they would like the participants of LifeGene to answer. During the last months, efforts have been devoted to making the questionnaire user friendly and well adjusted to the web-based format with which participants will interact.

- We have invested considerable effort into harmonising the questions. This has involved making all of them fit together as one questionnaire with the same language style. Since LifeGene will follow participants during a long period of time, harmonisation has also involved designing questions that can deliver comparable results over time, which will include a number of assessment occasions, says Mikael. It is vital that an answer given by a participant at one occasion can be compared with the answer given at another occasion.
- One such example is that answers given by an adolescent can be compared with answers given by the same person as an adult. We work in a continuous iterative process, where the research groups are giving us constant feedback, says Mikael Eriksson.

The total number of questions in the LifeGene “question-bank” is now about 2,500. However, each participant will be asked considerably fewer questions, approximately 500 on average. A screening method will insure that the participant will only be given questions that are relevant to her or him. The selection of what questions to ask a specific participant has involved a constant trade-off between user-friendliness and how much scientific information one can obtain.

- In total, all the questions will take about 60 minutes for an adult participant to complete. We have put considerable effort into ensuring that the questionnaire will not take longer, says Mikael Eriksson, who will continue to work with harmonizing the questionnaire during the spring and summer.

List of physical tests and measurements is now set

As with the questionnaire, researchers and specialists from various fields have held workshops and discussed what physical test measurements they would like to have included in LifeGene. The requests from the various research groups have been compiled and analysed to determine which tests will be of most value, as well as being feasible to conduct in the limited amount of time that the Test Center visit permits. The final decision on the physical tests and measurements for the LifeGene pilot has been made by the LifeGene Executive Committee, a group of scientists with expertise in key fields for the physical tests and measurements.

Kicki Kjaergaard at LifeGene is responsible for implementing tests at the LifeGene Test Centers.

- It is very important that the physical tests are not too time-consuming. The ones we have decided to do in the pilot take about 45 minutes to complete in total. It has been a trade-off between the amount of information that you can obtain and how long it takes for the participants to complete the tests, says Kicki.

The list of physical tests is now set for the pilot. For each participant, the following measurements will be taken: height, weight, waist circumference, blood pressure heart-rate and bioimpedance (a measurement of the percentage of body weight that is constituted of fat). Each participant will also undergo spirometry and audiometry

tests. We have been careful to select equipment for the physical tests that can be coupled into the LifeGene information system thus minimising the amount of manual data entry.

Agenda at the LifeGene Test Center

In the pilot study, as well as in the full scale study, participants will book their own appointments at the Test Center via their personal LifeGene homepage. At the center, participants will be greeted in the reception where their ID will be checked and they will give their written consent to participate in the study.

- Each participant will have one test leader who administers all the physical tests and measurements. The participants will come back to the center and repeat this procedure every five years, says Kicki.

Participants can choose whether or not they want to receive information about their test data. If they do, parameters such as blood pressure, spirometry and audiometry tests will be visible on their personal LifeGene homepage.

- If we find something that is not normal in these tests then we will refer the participants to their ordinary doctor or a specialist for further analysis. It is important to note that we will not examine the participants further nor will we provide diagnoses or treatments if something is abnormal in the tests, says Kicki Kjaergaard.

Blood tests

Apart from the questionnaire and the physical tests and measurements, participants will also leave blood samples both normal blood chemistries and storage in the biobank. Participants will also leave urine samples that will be stored in the biobank.

Blood tests will include parameters such as Hb, HbA1c, white bloodcells, cholesterol, as well as ALAT (relevant for the liver), kreatinin (relevant for the kidney), and cystatin C. Aside from the normal blood tests, blood will also be used for analysis of both cells and DNA, and as a basis for research within fields such as proteomics and epigenetics.

Questions?

If you have questions, please feel free to contact:

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What's next?

The summer and particularly the autumn will be extremely exciting for LifeGene! The pilot study with 5,000 participants will commence in September according to plan. We are currently working with the final preparations of the study. Participants will receive invitations in September to book an appointment at one of the LifeGene Test Centers. The duration of the pilot study will be approximately six months. When the pilot is completed in the spring of 2010, we will start the scale-up process before the full-scale study which will begin in the fall of 2010. You will hear more about that in the next newsletter which will be distributed in October. Until then, have a great summer!

Best Wishes



Nancy Pedersen
Director of LifeGene