Study Title: Crowdsourcing knowledge in heart disease (an Anonymous Patient Survey)

Dr. Peipei Ping, PhD from the Departments of Physiology and Medicine/division of Cardiology at the University of California, Los Angeles (UCLA) is conducting a research study.

You were selected as a possible participant in this study because you have a heart condition. Your participation in this research study is voluntary.

Why is this study being done?

The purpose of this research study is to gain a better understanding in the role of genes, proteins, and metabolites in heart disease, and to integrate this information with individual patient presentations and therapeutic outcomes. In this study, a repository will be constructed to catalog the decision-making experiences of patients, as well as their associated demographics and relevant clinical information. This information will be stored in an interactive web interface for patients to share and search for courses of interventions from medical cases similar to their own. With the information obtained during this study, we attempt to develop a web interface that will assist patients and their families to be better informed of their chosen course of intervention, and serve as a case-study resource for clinicians.

What will happen if I take part in this research study?

If you volunteer to participate in this study, the researcher will ask you to do the following:

Before you begin the study:
Before you begin the study, we will determine whether you are an eligible candidate to participate in this research study, based on your medical records. Whether you are eligible or not, has no relation with your clinical wellness.

During the study:
You will be subjected to interviews during which we acquire information about your personal experience on treatment for heart failure. It is completely your own choice if or how you want to answer the questions. In addition, we will look into your clinical records to obtain relevant information about your heart failure condition and therapy.

How long will I be in the research study?

We would like to have access to your clinical information for as long as we have your approval.

Are there any potential risks or discomforts that I can expect from this study?

There are no risks and discomforts upon participating in this study. We believe there are also no unknown risks and discomforts upon participating in this study.

Are there any potential benefits if I participate?

Possible benefits to me:
You will not directly benefit from your participation in the research study. No clinical decisions will be based on the results of the research tests done on your research biopsies or saliva.

Possible benefits to others or society:

There will be no direct benefit to you from participating in this study. This study will help the researchers learn more about your heart disease and possible healing treatments. Hopefully this information will help in the treatment of future patients with a heart failure condition like yours.

What other choices do I have if I choose not to participate?

Your alternative is not to participate in the study. If you choose not to participate in this research study, you will be subject to the usual clinical treatment for heart failure patients and heart transplant patients without any further consequences and without any prejudice.

Will I be paid for participating?

There will be no payment for your participation.

Will information about me and my participation be kept confidential?

Any information that is obtained in connection with this study and that can identify you will remain confidential. It will be disclosed only with your permission or as required by law. Confidentiality will be maintained as follows:

Use of personal information that can identify you:
The researchers will do their best to make sure that your private information is kept confidential. Information about you will be handled as confidentially as possible, but participating in research may involve a loss of privacy and the potential for a breach in confidentiality. Study data will be physically and electronically secured. As with any use of electronic means to store data, there is a risk of breach of data security.

Any information that is obtained in connection with this study and that can identify you will remain confidential. It will be disclosed only with your permission or as required by law. Confidentiality will be maintained by means of a non-identifying code system. All collected information and data will be discarded from any identifying information (i.e. names, numbers, birthdates, etc.) and linked to a study number.

People and agencies that will have access to your information:
The only people who will know that you are a research subject are certain members of the research team, and, if appropriate, your physicians and nurses, if necessary to protect your rights or welfare (for example, if you are injured and need emergency care)

How information about you will be stored:
When the results of the research are published or discussed in conferences, no information will be included that would reveal your identity. We will record your name and patient ID number one time and assign a study number to your biological samples and biopsies. The information containing your name will be stored and locked in our research office. Depending on the research results we might have to consult your medical records. In this case we would also keep the records locked in our research office.

Efforts will be made to keep your personal information confidential. We cannot guarantee absolute confidentiality. Our confidentiality does not prevent you or a member of your family from voluntarily releasing information about yourself or your involvement in this research. Note however, that if an insurer or employer, learns about your participation, and obtains your consent to receive research information, then the investigator may not use confidentiality to withhold this information. This means that you and your family must also actively protect your own privacy.

The research team, authorized UCLA personnel, the study sponsor National Institute of Health (NIH)/National Heart, Lung and Blood Institute, and regulatory agencies such as the Food and Drug Administration (FDA), may have access to study data and records to monitor the study. Research records provided to authorized, non-UCLA personnel will not contain identifiable information about you. Publications and/or presentations that result from this study will not identify you by name.

What are my rights if I take part in this study?

- **You can choose whether or not you want to be in this study, and you may withdraw your consent and discontinue participation at any time.**
- **Whatever decision you make, there will be no penalty to you, and no loss of benefits to which you were otherwise entitled.**
- **You may refuse to answer any questions that you do not want to answer and still remain in the study.**

Who can I contact if I have questions about this study?

- **The research team:**

If you have any questions, comments or concerns about the research, you can talk to the one of the researchers. Please contact:

David Liem, MD, PhD
Phone (laboratory): 310-2675624
Phone (cell): 310-709-2504
E-mail: dliem@mednet.ucla.edu

- **UCLA Office of the Human Research Protection Program (OHRPP):**

If you have questions about your rights while taking part in this study, or you have concerns or suggestions and you want to talk to someone other than the researchers about the study, please call the OHRPP at (310) 825-7122 or write to:

UCLA Office of the Human Research Protection Program
11000 Kinross Avenue, Suite 211, Box 951694
Los Angeles, CA 90095-1694

Instructions: Participation is voluntary and anonymous. Please answer the questions below by to the best of your ability. <u>For any questions, please contact AJLin@mednet.ucla.edu.</u>

Enter "N/A" if you prefer not to answer a question.

1. Please enter your age: ____

2. Please select your gender:
   - Male
   - Female
   - Prefer not to answer

3. Please enter your height in inches: ____

4. Please enter your weight in pounds (lbs): ____

5. Please select your ethnicity:
    - Non-Hispanic White or Euro-American
    - Black, Afro-Caribbean, or African American
    - Latino or Hispanic American
    - East Asian or Asian American
    - South Asian or Indian American
    - Middle Eastern or Arab American
    - Native American or Alaskan Native
    - Other: _____
    - Prefer not to answer
    - Don't know

6. Please select your highest level of education:
    - No schooling completed
    - Nursery school to 8th grade
    - Some high school, no diploma
    - High school graduate, diploma or the equivalent (for example: GED)
    - Some college credit, no degree
    - Trade/technical/vocational training
    - Associate degree
    - Bachelor's degree
    - Master's degree
    - Professional degree
    - Doctorate degree
    - Other: _____
    - Prefer not to answer

7. Please select your marital status:
    - Single, never married
    - Married or domestic partnership
    - Widowed
    - Divorced
    - Separated
    - Other: _____
    - Prefer not to answer

8. Please select your employment status:
    - Employed for wages
    - Self-employed
    - Out of work and looking for work
    - Out of work but not currently looking for work
    - A homemaker
    - A student
    - Military
    - Retired
    - Unable to work

9. Please select the types of diets you have had for longer than 2 months:
    - Vegetarian
    - Vegan
    - Pescetarian (no meat except fish)
    - Pork-free

- Gluten-free
- Lactose-free
- No special diet
- Other: _____
- Prefer not to answer

10. Please select your current diet:
    - Vegetarian
    - Vegan
    - Pescetarian (no meat except fish)
    - Pork-free
    - Gluten-free
    - Lactose-free
    - No special diet
    - Other: _____
    - Prefer not to answer

11. Please select how often you consume alcohol on a regular basis:
    - Only socially
    - 1 drink per day
    - 2+ drinks per day
    - 1-3 drink per week
    - 4+ drinks per week
    - Monthly
    - Never
    - Prefer not to answer

12. Please select how often you use recreational drugs on a regular basis:
    - Only socially
    - 1 time per day
    - 2+ times per day
    - 1-3 times per week
    - 4+ times per week
    - Monthly
    - Never
    - Prefer not to answer

13. Please select how often you perform aerobic exercise:
    - 1 time per day
    - 2+ times per day
    - 1-3 times per week
    - 4+ times per week
    - Monthly
    - Never
    - Prefer not to answer

14. Please select how often you consume junk food (i.e., candy, fast food, etc):
    - 1 time per day
    - 2+ times per day
    - 1-3 times per week
    - 4+ times per week
    - Monthly
    - Never

- Prefer not to answer

15. Please select how many hours of sleep you get regularly a night:
    - <3 hours
    - 3-6 hours
    - 6-8 hours
    - 8-10 hours
    - >10 hours
    - Other: _____
    - Prefer not to answer

16. On a scale of 1 (very little) – 10 (a lot), how stressful do you typically find your daily life?
    - 1
    - 2
    - 3
    - 4
    - 5
    - 6
    - 7
    - 8
    - 9
    - 10

17. Please enter the appropriate measures for the following if known:
    - Total cholesterol: ____
    - LDL (low-density lipoprotein),the "bad cholesterol": ____
    - HDL (high-density lipoprotein), the "good cholesterol": ____
    - Triglycerides, another form of fat in the blood: ____

18. Please select how many hours of sleep you get regularly a night:
    - <3 hours
    - 3-6 hours
    - 6-8 hours
    - 8-10 hours
    - >10 hours
    - Other: _____
    - Prefer not to answer

19. Please select how many hours of sleep you get regularly a night:
    - <3 hours
    - 3-6 hours
    - 6-8 hours
    - 8-10 hours
    - >10 hours
    - Other: _____
    - Prefer not to answer

20. Please select your blood type:
    - O+
    - O-
    - A-
    - A+
    - B-

- B+
- AB-
- AB+
- Prefer not to answer
- Don't know

21. Please enter your blood pressure: ____/____

22. Please enter your previous city(ies) of residence: ____
    - How long have you lived in each city? ____

23. Please enter your current city of residence: ____
    - How long have you lived in each city? ____

24. Please enter any past/current medical conditions you may have: ____

25. Please enter information regarding your history of present illness:
    - How long have you had your present illness? ____
    - On a scale of 1 (very little) – 10 (a lot), how much does your illness impact your daily functioning?
        - 1
        - 2
        - 3
        - 4
        - 5
        - 6
        - 7
        - 8
        - 9
        - 10

26. Please enter any family medical conditions (i.e., heart disease, diabetes, genetic disease, etc): ____

27. Please enter the names of any current medications: ____

28. Did you have more than one possible interventions option?
    - Yes
        - If yes:
            - What interventions were options? ____
            - What intervention was used? ____
                - On a scale of 1 (very little) – 10 (a lot), how much did this intervention improve your quality of life?
    - No

29. Please describe your patient intervention experience in as much detail as possible. For example, please detail the situation you were in, the obstacles you overcame, the decisions you had to make, and what you would have done differently.

30. What would you recommend to a patient who is going through the same situation you went through?

When you are satisfied with your answers, please submit your anonymous survey by clicking on the button below.

Submit

Thank you for your participation.