UNIVERISITY OF ILLINOIS AT CHICAGO
Research Subject Authorization Confidentiality & Privacy Rights
Health Insurance Portability and Accountability Act (HIPAA)

Protocol Title: Hispanic Community Health Study/Study of Latinos (HCSH/SOL)

Principal Investigator Name and Title: Martha L. Daviglus, MD, PhD – Vice Chancellor for Research; Director- Institute for Minority Health Research (IMHR); Professor of Medicine.

Address and Contact Information: 1819 W. Polk Suite 246, Chicago, IL 60612
Tel. 312.413.0739 Email. daviglus@uic.edu

Emergency Contact Name and Information: Cesar Alvarado – Project Coordinator
Institute for Minority Health Research
840 S Wood Suite 120, Chicago, IL 60612
Tel. 312.413.3254 Email, calvar3@uic.edu

You have agreed to participate in the research Study mentioned above and have signed a separate informed consent that explained the procedures of the research Study and the confidentiality of your personal health information. This authorization form gives more detailed information about the following:

- What personal health information about you will be collected in this Study
- Who will use your information within the institution and why
- Who may disclose your information and to whom
- Your rights to access your personal health information during the Study
- Your right to withdraw your authorization (approval) for any future use of your personal health information

By signing this document you are permitting your doctors and other health care providers to disclose personal health information collected about you to the University of Illinois at Chicago and the researcher listed above for purposes of the Study. You are also allowing UIC and the researcher to disclose that personal health information to outside organizations or people involved with the processing of this Study, as described in the separate informed consent form.

What personal information is collected and used in this Study, and might also be shared (disclosed)?

The following personal contact and personal health information will be collected, used for this research Study and may be disclosed or released during your involvement with this research Study:

- Name
- Address
- Relatives' names or addresses
- Telephone number
- Participant ID number
- Social Security numbers
- Enrollment Date
- Medical Record number
- Hospitalization/Emergency department records

Other tests and procedures that will be performed in the Study include:

· Height and Weight Measurements
· Blood Pressure
· An echocardiogram an exam of your heart
· A dental examination
· Blood sugar test for diabetes
· A test for cholesterol levels

It also includes questions about:
· Nutrition
· Stress and depression
· Work and home environment
· Physical activity and eating habits
· Family medical history

Why is your personal information being used?
Your personal contact information is important for the University of Illinois research team to contact you during the Study. Your personal health information (including the results of tests and procedures) is being collected during this research Study for purposes of the Study. The Principal Investigator may also use the results of these tests and procedures to treat you.

Who within the University of Illinois at Chicago may use or disclose your personal health information?
The following individuals and organizations within the University of Illinois at Chicago may use or disclose your personal health information for this research project:

- The Principal Investigator and the Investigator's Study team (other University staff associated with the Study)
- The University of Illinois at Chicago Institutional Review Boards (the committees charged with overseeing research on human subjects)
- The University of Illinois at Chicago Office for the Protection of Research Subjects (the office which monitors research studies)
- Authorized members of the University of Illinois at Chicago workforce who may need to access your information in the performance of their duties (for example: to make sure the research is being done correctly).

Who outside of the University of Illinois at Chicago might receive your personal health information?
As part of the Study the Principal Investigator, Study team and others listed above, may disclose your personal health information, including the results of the research Study tests and procedures. to the following:

- Other academic research center(s) who are also working on the Study
- University of North Carolina Chapel Hill Collaborating Center
- National Heart, Lung, and Blood Institute (NHLBI) who is sponsoring the study
- Government agencies such as the Food and Drug Administration and Office of Human Research Protection
- Other health care providers who are part of the Study (e.g., laboratories who perform tests)
- The University of Illinois at Chicago Institutional Review Board
- the University of Illinois Medical Center and its representatives, and other persons who watch over the safety, effectiveness, and conduct of research.

The personal information of yours that is disclosed in connection with the Study may no longer be protected by the federal privacy protection regulations.

- In records and information disclosed outside of the University of Illinois at Chicago, you will be assigned a unique code number. The Principal Investigator will ensure that the key to the code will be kept in a locked file. The key to the code will be destroyed at the end of the research Study.

How long will the University of Illinois at Chicago be able to use or disclose your personal health information?
Your authorization for use of your personal health information for this specific Study does not expire. This information may be maintained in a research repository (database). However, the University of Illinois at Chicago may not re-use or re-disclose your personal health information collected in this Study for another purpose other than the research Study described in this document unless it obtains permission to do so from the University of Illinois at Chicago Institutional Review Board.

Will you be able to access your records?
Results of all tests and procedures done solely for this research Study and not as part of your regular care and will not be included in your medical record. You will be able to request access to your medical record when the Study is completed.

During your participation in this Study, you will have access to your medical record and any Study information that is part of that medical record. The investigator is not required to release to you information in the research records.

How will your health information be protected?

The researchers at the University of Illinois at Chicago and all sponsoring organizations listed above agree to protect your health information and will only share this information as described within this research consent/authorization form.

When your health information is given to people outside of the research study, those agencies that receive your health information may not be required by federal privacy laws (such as the Privacy Rule) to protect it. They may also share your information with others without your permission, if permitted by laws that they have to follow.

Can you change your mind?
You may withdraw your permission for the use and disclosure of any of your personal information for research, **but you must do so in writing** to the Principal Investigator at the address on the first page. Even if you withdraw your permission, the Principal Investigator for the research Study may still use your personal information that was collected prior to your withdrawal of permission if that information is necessary to the integrity of the Study. If you withdraw your permission to use your personal health information that means you will also be withdrawn from the research Study.

If you withdraw your permission to use any blood or tissue obtained for the Study, the Principal Investigator will ensure that these specimens are destroyed or will ensure that all information that could identify you is removed from these specimens.

What are my rights as a research subject?

If you have questions or concerns regarding your privacy rights under HIPAA, you should contact the University of Illinois at Chicago Privacy Officer at Ph: (312) 996-2271.

You are not required to sign this authorization. If you decide not to sign the authorization:

Right to Refuse to Sign this Authorization

You do not have to sign this Consent/Authorization. However, because your health information is required for research participation, you cannot be in this research study if you do not sign this form. If you decide not to sign this Consent/Authorization form, it will only mean you cannot take part in this research. Not signing this form will not affect your non-research related treatment, payment or enrollment in any health plans or your eligibility for other medical benefits.

If you have not already received a copy of the Notice of Privacy Practices, you should ask for one.

Your signature below indicates that you are providing both consent to participate in the research study and authorization for the researcher to use and share your health information for the research.

_____ _____

Signature of Subject Date

_____

Printed name of Subject

_____ _____

Signature of Witness Date (must be same as Subject's)

_____

Printed name of Witness

_____ _____

Signature of Parent / Guardian or Legally Authorized Representative of Subject

Date (must be same as Subject's)

_____

Printed name of Parent / Guardian or Legally Authorized Representative of Subject

Describe relationship to subject including the legal authority this individual has to act on behalf of the subject. (Check one below)

- ☐ Parent
- ☐ Medical Power of attorney/representative
- ☐ Legal guardian
- ☐ Health care surrogate
- ☐ Other; specify

_____