The state of Oregon has recently passed laws about coded and anonymous genetic research. All direct health care providers in the state of Oregon are now required to ask their patients whether they want to have their medical information and/or biological specimens (blood, urine, or other tissue specimens collected from your body) used for "coded" or "anonymous" genetic research. This type of research uses medical information or biological specimens gathered as a part of your clinical care. It does not require any extra contact with you.

You may decide whether or not you want this information to be available for use in research. It's your choice. Your decision will not affect the care you receive from Legacy Health System. It also will not affect your health insurance coverage.

## Your Rights— Regarding Coded and Anonymous Genetic Research

#### What is the purpose of research?

Research is important because it gives us valuable information on how to improve health, such as ways to prevent or improve treatment for heart disease, diabetes, and cancer. Under Oregon law, a special team reviews all genetic research study requests before any research begins. This team makes sure that the benefits of the research are greater than any risks to participants.

## What is coded or anonymous genetic research?

**Genetic research** means research using human DNA samples, genetic testing or genetic information. **Genetic tests** are tests for determining the presence or absence of genetic characteristics in a human individual or the individual's blood relatives.

<u>Coded</u> means identifiable only through the use of a key that links a DNA sample or genetic information to an individual or the individual's blood relative. The key to the code is kept separate from the specimen or medical information, so the researcher is unable to link it to the individual.

**Anonymous research** means scientific or medical genetic research conducted in such a manner that any DNA sample or genetic information used in the research is uniden-

tified. It does **not** include research conducted in such a manner that the identity of an individual, or the identity of an individual's blood relatives, can be determined by use of a code, key or other means of linking the information to a specific individual.

#### Who is a direct health care provider?

A <u>direct health care provider</u> is one who assesses and treats you. There are many of these in the health care setting. Examples of these are your hospital, physician, nurse, physical therapist and pharmacist.

# If I don't want my information or specimens used for this purpose, what do I do?

You will need to sign Legacy's "Notice of Your Right to Decline Participation in Future Anonymous and/or Coded Genetic Research," and check the box marked, "I decline."

#### What happens if I do nothing?

If you choose to do nothing, then your information and specimens may be used for coded or anonymous genetic research. If it's OK with you that researchers use your test results, specimens or other information, you don't need to do anything.

## What if I'm just not sure what to do at this time?

No matter what you decide now, you can always change your mind later. If you change your mind, tell each of your health care providers your decision in writing. The new decision will apply only to medical information or specimens collected after your health care provider receives written notice of your new decision.

# Am I going to be asked about this every time I go to the doctor's office or hospital?

No. Health care providers need only ask you once, although you can change your mind at a later date, as noted above.

For more information, contact the

or contact the Oregon Genetics Program,

971-673-0271, www.oregongenetics.org

Legacy's Compliance Hotline at 503-415-5555,

### Legacy Health System



Legacy Health System, a non-profit organization, includes Emanuel Hospital & Health Center, Emanuel Children's Hospital, Good Samaritan Hospital & Medical Center, Meridian Park Hospital, Mount Hood Medical Center, Salmon Creek Hospital, Legacy Clinics and CareMark/Managed HealthCare Northwest PPO. ©2006

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