**ROCHESTER EPIDEMIOLOGY PROJECT**

**1966-2016**

**Improving health globally by studying health locally**

**A collaboration in Minnesota and Wisconsin**

# www.rochesterproject.org

## What is the Rochester Epidemiology Project?

The Rochester Epidemiology Project (REP) is a collaboration of clinics, hospitals, and other medical and dental organizations in Minnesota and Wisconsin. Its combined data – a unique national resource – comes from community members who have agreed to share their medical records for research.

Using information from medical records, researchers can discover what causes diseases, how patients respond to medications and surgery, and what will happen to patients in the future.

The REP allows us to answer questions that cannot be answered anywhere else. Read on for some of those answers.

# THE REP WAS 'BIG DATA' BEFORE BIG DATA WAS COOL!

**50 YEARS** accumulating, linking, and analyzing data for medical research

**2,600+ PUBLICATIONS** from REP data

**550+ THOUSAND RESIDENTS** from Olmsted County, Minnesota, and now thousands more participants across 27 counties

**200+ MILLION** medical diagnoses, surgeries, prescriptions, lab tests, dental procedures and immunizations — safely stored, securely linked, and invaluable to understanding diseases and finding ways to improve health

## REVOLUTIONIZING HEALTH CARE AND RESEARCH THROUGH DATA

"The REP allows the study of health and disease across the entire community from birth to death, and from primary to specialty care."

**— Barbara Yawn, M.D., REP Co-Principal Investigator, 2006-2015**

### Will anesthesia hurt my child's brain?

A REP study published in 2012 showed that children who receive general anesthesia before age 2 are at increased risk for the later development of attention-deficit hyperactivity disorder (ADHD). This study led to new guidelines recommending delay of surgical procedures that require general anesthesia in small children if possible.

### Does head trauma damage the brain?

Studies using the REP showed us that head trauma could lead to dementia, Parkinson's disease, and epilepsy – sometimes decades after the trauma.

This knowledge informed the U.S. Congress when they were determining how to compensate military personnel who experienced head trauma. This knowledge is also guiding research on interventions that may break the link between trauma and damage to the brain.

### Should women have their ovaries removed to prevent cancer?

A series of studies using the REP have shown that for the majority of women who do not have a high genetic risk of ovarian cancer, removing the ovaries before reaching menopause is more harmful than preventive. These studies have changed the practice of ovarian surgery both locally and globally.



### Why do your bones break when you fall?

A REP study showed that the risk of breaking the hipbone increases with age, and that people who break their hip are at increased risk of dying. The study also showed that the risk of hip fracture went up and down over 65 years of study. The REP allows us to conduct unique long-term population studies that address important public health issues, often pointing the way to solutions.



### Good news: the risk of dementia has been going down. How do we keep that going?

As people age, they often develop Alzheimer's disease. The REP helps identify risk factors for Alzheimer's disease, an important step in finding ways to stop or reverse the process. A REP study published in 2011 was one of the first to suggest that the risk of dementia has gone down in the U.S. in recent years. If we understand why fewer people get dementia, we may be able to reduce the risk further.

"In medicine, many important questions remain unanswered, and many answers that we think we have, remain questionable."

— Chinese proverb adapted to medicine by Walter Rocca, M.D.

# WHAT CAN YOU DO TO HELP?

**1**

### BE AWARE
We would like you to be aware of the importance of using medical records data to improve our medical knowledge and our ability to care for you, your family, and your community.

**2**

### SAY YES
Members of the community receiving health care services for the first time are asked if they will allow their medical records to be used for research. We hope you will say yes when asked and become part of the REP community.

**3**

### PARTICIPATE ACTIVELY
You may be invited to participate in a special study with a telephone or mail survey, asked to give a blood sample or have some diagnostic tests. Please consider accepting these invitations.

**Are you part of the REP? Call us to find out. 1-877-276-6654**

# COUNTIES IN THE REP



WISCONSIN

MINNESOTA

Barron

Chippewa

Dunn

Eau Claire

Pepin

Buffalo

Trempealeau

Nicollet  Le Sueur  Rice  Goodhue

Wabasha

Brown

Watonwan  Blue Earth  Waseca  Steele  Dodge  Olmsted  Winona

La Crosse

Martin  Faribault  Freeborn  Mower  Fillmore  Houston

# Why is medical record research important?

**UNDERSTANDING DISEASE**

When you are sick, your doctor uses medical knowledge to understand the causes of your disease, to decide what treatment to give you, and to tell you what to expect in coming years. Your doctor's medical knowledge comes mainly from clinical studies in which researchers compare groups of people with or without a disease (e.g., with or without breast cancer) or with or without a characteristic (smoking or not smoking). These studies provide continuously improving evidence to guide your medical care.

**IMPROVING CARE**

Every time a doctor sees you, information about you is collected such as your weight, blood pressure and any medication you are taking. These data can be organized in big electronic databases, and then used to conduct clinical studies. Powerful computers allow us to analyze these very big databases for research.

The Rochester Epidemiology Project has a huge collection of data from individuals like you who live in Olmsted County as well as others across 27 counties in Minnesota and Wisconsin. These data are used every day to advance our medical knowledge and to improve the care that you receive.

**SOLVING HEALTH CARE PROBLEMS**

By studying the medical conditions in our community, we can find solutions to health problems that affect not just ourselves and our neighbors, but people across the nation and around the world.

All medical information in the REP is safe and protected. Information from any particular patient is combined with information from many other patients, so it becomes impossible to tell which persons are included in the study. However, that combined information is priceless for medical research.