“Without clinical research, progress in improving health and treatment of disease would not be possible. To achieve success, clinical research needs collaboration between volunteers, patients and researchers.”

—Pamela Ouyang, M.D., director, Johns Hopkins Women’s Center for Cardiovascular Health

“Since becoming a research participant, I feel obligated and compelled to challenge other African Americans to participate in research so they, too, can become a part of the solution. You can make a difference by getting involved in research trials and educating your respective communities about memory loss.”

—Ernestine Jolivet (right), research participant, Johns Hopkins Memory & Alzheimer’s Treatment Center

“I can’t guarantee that research will help you or your loved one, but I can promise you that it will have an impact on the lives of future patients.”

—Paul Rosenberg, M.D., associate director, Johns Hopkins Memory & Alzheimer’s Treatment Center
Johns Hopkins Bayview Medical Center is an academic medical center with physicians who are full-time faculty at The Johns Hopkins University School of Medicine. Many of these faculty are actively involved in cutting-edge research, which is happening throughout the campus in a variety of health fields.

This brochure will explain clinical research and tell you how you can get involved in research at Johns Hopkins Bayview.
What is a clinical research study?

A clinical research study helps doctors and nurses find ways to prevent, detect and treat illnesses. Each study tries to answer important health questions, such as “What causes high blood pressure?” or “What is the best way to treat high blood pressure?” This information teaches patients and families what they can do to get well and stay healthy.

- **Prevention studies** look for better ways to keep people from getting sick. These studies often involve people who are at risk for a certain disease.
- **Screening studies** find the best ways to detect health conditions.
- **Treatment studies** test how well medicines, vitamins, therapies and surgical treatments work.
- **Quality of life research** looks for ways to improve the comfort of people with chronic illness. Topics include sleep, mobility and ability to work.
- **Observational studies** monitor health over a period of time to help us understand how a health condition impacts people. These studies do not involve medications or treatments.
Who can participate in clinical research?
Anyone can choose to take part in a research study. If you decide to participate, you will be “screened” to see if you meet the requirements for the study. Some studies need healthy people and others need people with a health condition. Research studies also look for volunteers of all ages, and ethnic and cultural backgrounds.

Are there risks in participating in a research study?
Things are very different in research than they were decades ago. There was a time when there were no protections in place for participants of clinical research, such as the Tuskegee study in Alabama.

Since then, federal laws and regulations require Institutional Review Boards (IRB) to monitor safety and protect the rights of volunteers. The IRB includes doctors, researchers, community leaders and members of the faith community.

What are the benefits of participating in a research study?
When you participate in a research study, you are helping doctors and nurses find new ways to control and treat medical conditions. The results of these studies may change and improve how illnesses are treated in the future.

In some studies, you may personally benefit by receiving research-related health care, counseling or medicine at no cost.

What should I consider before I volunteer?
Volunteering for a research study is a personal choice, and you should think about the risks and benefits before you sign up.

• Talk to your doctor or nurse. He or she may be able to tell you if there is a study for a specific disease or condition, and how it might benefit you.
• **Talk to the researchers.** Ask any questions you may have to help you decide if a research study is the right choice for you. You can find sample questions at the end of this booklet.

• **Talk to family or close friends.** Participating in a research study is a personal decision. It is often helpful to talk with someone you trust before deciding to volunteer.

**How can I learn more about research at Johns Hopkins Bayview?**

• **Visit hopkinsbayview.org/studies or trials.johnshopkins.edu.** Studies are listed by health condition and topic. If you see a study that interests you, contact the research team.

• **Call 410-550-0681.** A staff member will help you find a study that may be right for you.

**What happens once I volunteer for a study?**

Once you decide to participate in a clinical research study, the doctor or nurse involved will tell you what to expect, including the length of the study; how often and how many times you will need to visit the hospital; and the known risks and benefits associated with study treatment. You will then be asked to sign a form with privacy information and other details about the study. As soon as you sign the form, you can begin the study.

With most clinical research, you may receive medical evaluations, laboratory tests, medications and treatment at no cost. You may be paid for your participation.
Questions you may want to ask the research staff before you volunteer for a research study:

- What is the purpose of this study?
- What are the credentials and research experience of the physician and study staff?
- What will I be asked to do?
- How long is the study going to last?
- Do study participants get paid or reimbursed?
- Does the study cost me money?
- Who pays for the study?
- How will the treatment be given?
- What has been learned about the study treatment so far?
- Does the study involve a placebo (inactive medication) or a treatment that is already on the market?
- How will I know if the treatment is working?
- If the treatment works for me, can I continue taking it?
- What will happen to me if the treatment doesn’t work?
- What do you do with the blood or urine samples taken from me?
- What happens with the data or information that is collected about me?
- What if I get sick while I am in the study?
- What happens if I want to stop participating in the study?
- Will my medical care be affected if I stop participating in the study?
- Can anyone find out if I’m participating in research?
- What happens when the study is over?
Directions to Johns Hopkins Bayview

From points South (including BWI Airport):
Take I-295 north to the Harbor Tunnel Thruway (I-895). After exiting the tunnel, take exit 12, Lombard St. At the first stop light, proceed straight onto Bayview Blvd.

or

Take I-95 north through the Fort McHenry Tunnel to exit 59, Eastern Ave. Turn left onto Eastern Ave. and proceed approximately one mile to Bayview Blvd. on the right.

From points North and East:
Take I-95 south to exit 59, Eastern Ave. Turn right onto Eastern Ave. (west) and proceed about one mile to Bayview Blvd. on the right.

or

Take I-895 south to exit 12, Lombard St. At the first stop light, turn right onto Bayview Blvd.

Direction Line: 410–550–5748