COMMUNITY PULSE –

Brought to you by the JOHNS HOPKINS INSTITUTE FOR CLINICAL & TRANSLATIONAL RESEARCH

Events Calendar

2016

October 2, 9, 16 & 23 Free Prostate Cancer Screening at local churches

Chesapeake Urology is offering free prostate cancer screening. All screenings include a PSA test, DRE exam, and health education. For information go to: www.chesapeakeurology.com/about/free-prostate-cancer-screenings/

Sunday, October 2, 2016 • 8 AM – 2 PM Church of the Redeemed of the Lord Church 4321 Old York Road, Baltimore, MD 21212

Sunday, October 9, 2016 • 8 AM – 2 PM Mount Olive Freewill Baptist Church 618 N. Hammonds Ferry Road, Linthicum, MD 21090 Sunday, October 16, 2016 • 8 AM – 2 PM Wayland Baptist Church 3200 Garrison Boulevard, Baltimore, MD

Sunday, October 23, 2016 • 12 PM – 4 PM Mt. Pleasant Baptist Church & Ministries, Go Pink Go Blue Health Fair 6000 Radecke Avenue, Baltimore, MD 21206

November 5

African-American Community Forum on Memory Loss Saturday, November 5, 2016 • 8 AM – 3 PM

Coppin State University, 2500 West North Avenue, Baltimore, MD 21216 The Alzheimer's Association will host the 12th Annual Pythias A. and Virginia I. Jones African American Community Forum on Memory Loss.

Topic: Alzheimer's Disease: Community Awareness, Empowerment, and Engagement. **Keynote Speaker:** Goldie Byrd, Ph.D., Dean, of the College of Arts and Sciences, North Carolina A&T University.

For more information, contact Junnell Daniels at jdaniels@alz.org.

November 12

Journey to Hope Conference

Saturday, November 12, 2016 • 8:30 AM – 2 PM Asthma & Allergy Center Atrium Johns Hopkins Bayview campus

5501 Hopkins Bayview Circle, Baltimore, MD 21224

The Johns Hopkins Memory & Alzheimer's Treatment Center and Alzheimer's Disease Research

Center will host the 9th Annual Journey to Hope Conference.

Topic: Best Practices and Activities in Dementia Care.

Keynote Speaker: Steve Vozzella BA, ACC, Mid-Atlantic Health Care.

For more information, contact Octavia Byrd at obyrd2@jhmi.edu.

Within this issue, the Johns Hopkins Institute for Clinical and Translational Research highlights programs that promote community engagement in the research process. The Research Participant Community Partnership Core (RPCP Core) includes programs focused on community engagement, research participant recruitment and retention, research participant advocacy, and research ethics. For more information, contact Crystal Evans at cevans20@jhmi.edu.

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Community Research Advisory Council **Events & Programs Honoring**

Henrietta Lacks





Henrietta Lacks Memorial Lecture

Held the 1st or 2nd Saturday in October at Johns Hopkins University. This free event honors the global impact of Henrietta Lacks and HeLa cells, explores social and ethical issues affecting public health, and provides updates on research activities. Sponsor: The Johns Hopkins Institute for Clinical and Translational Research

Henrietta Lacks School Visits & Symposiums

Held once a year in April or May, additional programs convened upon request. This program supplements classroom reading of the Immortal Life of Henrietta Lacks and provides students an opportunity to learn from members of the Lacks Family, scientists conducting HeLa research, and to explore career and educational opportunities at Johns Hopkins. Sponsors: The Johns Hopkins East Baltimore Community Affairs Office and the Johns Hopkins Institute for Clinical and Translational Research.

Henrietta Lacks Community Health Book Club

Held, once a month from July to September.

Club meetings are convened at Turner Station Sollers Point Multipurpose Center, Johns Hopkins University, and Memorial Baptist Church. Through reading books, participants explore ethical and social issues affecting medicine and research. The book club is free and open to the public. Sponsor: The Johns Hopkins Institute for Clinical and Translational Research. For more information, contact Barbara Bates-Hopkins at bhopkin1@jhu.edu or 410-502-5651.

Mentoring and Scholarship

Henrietta Lacks Dunbar Health Science Scholarship

Provided to 11th graders at Paul Laurence Dunbar High School pursuing a career in medicine or health science.

Hopkins invites students who complete the entire application process to join a mentoring program sponsored by the Office of Student Diversity.

Funding Community University Partnerships

Henrietta Lacks Memorial Award is a grant that provides funding and support for community groups and Johns Hopkins staff/students who collaboratively develop a program that serves the Greater Baltimore Region. The Urban Health Institute sponsors this grant program. For more information, contact Amy Gawad at agawad1@jhu.edu or 410-502-7473.

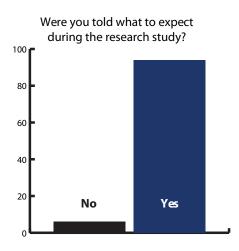
THE COMMUNITY DAY AT THE IRB PROJECT

"The Community Day at the IRB" project was created to help inform the community about the IRB. The aim is to allow individuals to see firsthand how the Johns Hopkins IRB reviews human subject's research studies. The group met December 14, 2015 and August 15, 2016, and included members of the Community Research Advisory Council (C-RAC). Participants received a brief overview of the IRB's operations, attended an IRB meeting, spoke with a community representative. Dr. Joseph Carrese, the chair of one of the IRBs said, "It was very helpful to the Board members to have this interaction and learn what was of interest and of concern to the CRAC members." It is planned to have more Community Day at the IRB sessions in the near future. If you'd like to participate or to get more information, please contact Fred Luthardt at fluthar1@jhmi.edu.



Institutional Review Boards (IRBs)

Many people don't know that there is a group of people that looks at human research studies to make sure they are safe for the persons who join them. This group is known as an Institutional Review Board, or "IRB." So, what does the IRB do? The U.S. government requires the IRB to review, approve, and monitor the safety of all research that involves people. Before the research begins, the IRB makes sure that the study is safe, ethical, and in line with high scientific standards. The IRB only approves studies if the risks of taking part does not outweigh the benefits and if the rights of participants are protected. The IRB also reviews the progress of a study at least once a year and oversees how the research is conducted. Each IRB must have at least one member from the community who is a non-scientist (for example, a lawyer, religious leader, or teacher).



Research Participant Satisfaction Survey

This year, we asked 170 people who had recently participated in a research study at Johns Hopkins about their experiences. People responded that they were largely satisfied. 94% reported that they would probably or definitely recommend joining a research study to their family and friends. Overall, people were very happy with the research team members. Over 95% reported they were usually or always treated with respect and listened to carefully by the research team members. Additionally, over 95% reported that they were told what to expect during the study and felt prepared for their experience in the study. People answered questions about reasons to participate in a study. 85% stated that finding out more about their disease was a very important reason to join a research study; over 90% stated that helping others was a somewhat or very important reason to join a research study. 78% stated that earning money or payment was not important at all to their decision to join a research study. The majority of participants stated that improved health or quality of life, finding out more about their disease, gaining new access to treatment, helping others, the health center's reputation, and concern about the study topic were very important reasons for staying in a study. Importantly, 80% responded that a summary of overall research results shared with them would be important for them in future studies. We are happy with the high level of satisfaction seen in these results, and will continue to improve our efforts to ensure research participants have positive, rewarding experiences.

The Community Research Advisory Council (C-RAC)

What is the Community Research Advisory Council (C-RAC)?

The C-RAC is an advisory board that consists of community members, researchers, faculty, and staff who help shape research and outreach activities conducted by Johns Hopkins and other organizations. The C-RAC formed in 2009 to create a forum for patients, families, community members, and scientists to discuss research that tackles issues that affect people living in Baltimore.

How Has the C-RAC Served the Community?

Each year, the C-RAC hosts forums within the community to discuss research. For example, in 2016, the C-RAC hosted the Community Forum on Healthy Aging Research that connected 120, patients, local residents, and researchers. The next forum will occur on Monday, June 5, 2017, 4 PM – 8 PM at Johns Hopkins Bayview. The C-RAC helped organize focus groups within the local community to find out the neighborhood and social factors that impact patient management of Type 2 Diabetes. Several members volunteer twice a month at the Day at the Northeast Market, an outreach program that connects local residents with health resources and research opportunities.

How Has the C-RAC Impacted Health Research?

The C-RAC also works with researchers to make their projects more relevant to the community. For example, in 2013, a researcher asked for advice in how to engage Baltimore City residents and community groups in a study evaluating how often intravenous drug users were also infected with Hepatitis C. The C-RAC recommended that they train several people who had participated in the study to serve as research ambassadors who educate and encourage people to get involved in the study. In 2016, the research team trained six research ambassadors who have helped increase community involvement in the study. The C-RAC also serves as the community advisory board for the Center of Excellence in Environmental Health Disparities, within this role, members review research projects on Childhood Asthma and Chronic Pulmonary Obstructive Disease.

How can I join the C-RAC?

For more information, contact Crystal Evans at cevans20@jhmi.edu.





C-RAC Members: Crystal Evans, Fred Luthardt, Sharon Hunt, Barbara Bates Hopkins, Pat Tracey, and Inez Robb presented a poster describing how the C-RAC assists researchers at the Advancing the Science of Community Engagement Conference, August 25

FIND A RESEARCH STUDY **AT JOHNS HOPKINS**



Many people might consider participating in research but do not know how to find studies that are right for them. The Johns Hopkins Institute for Clinical and Translational Research helps connect people with research opportunities.

Trials @ Hopkins is a searchable online database of the clinical research that is taking place right now at Johns Hopkins.

Trials @ **Hopkins** can point you to a study that is looking for research participants just like you!

http://trials.johnshopkins.edu/





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