

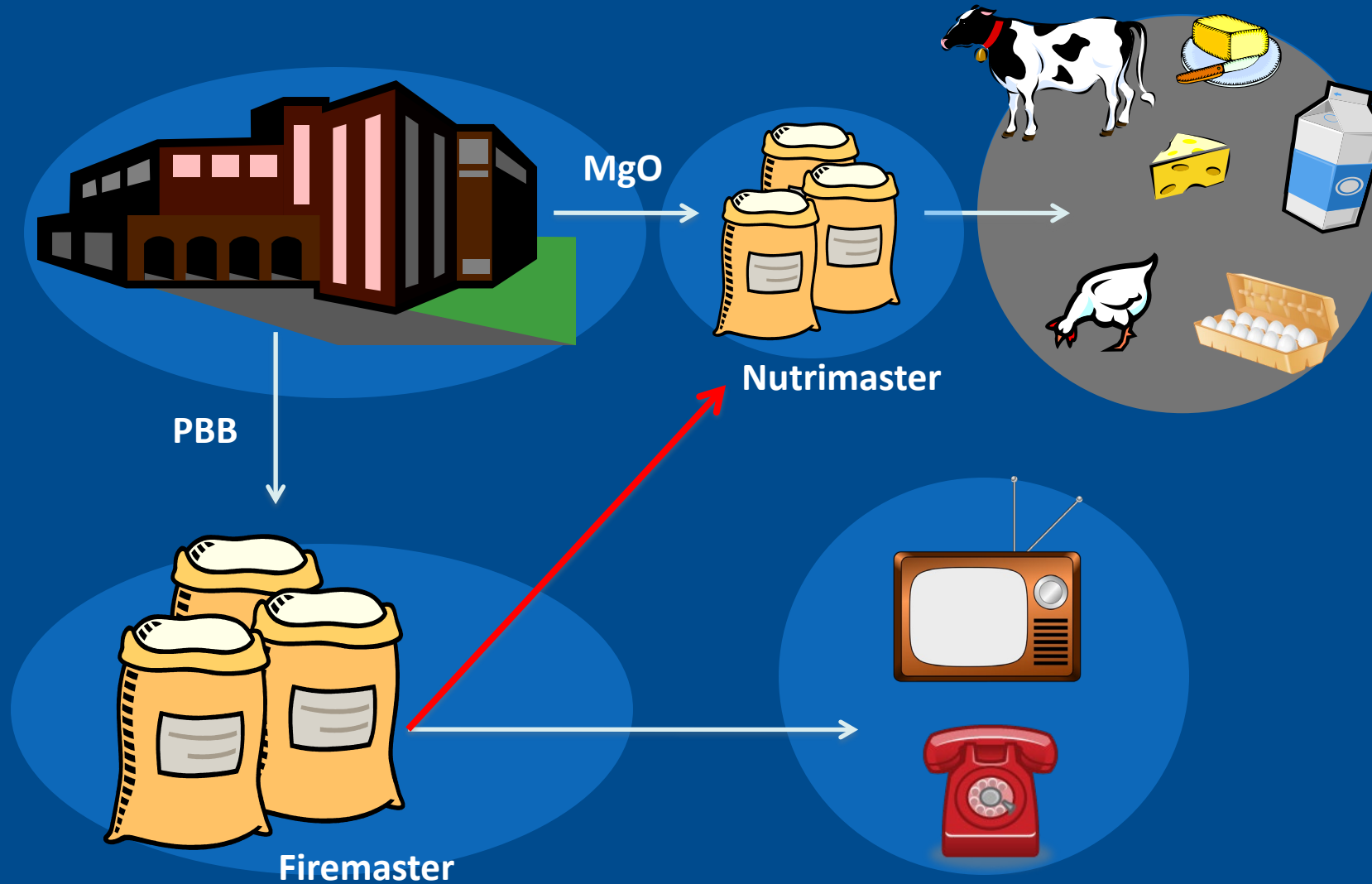
The Michigan PBB Registry: Community partners provide a way forward during the pandemic

Michele Marcus, Lead Scientist

Melanie Pearson, Community Engagement Lead

Bonnie Havlicek, Co-chair of the PBB Citizens Advisory Board

Velsicol Chemical Plant Disaster



Research Findings

- Can be transferred from mother to child in the womb and through breast milk
 - “I didn’t know that something that I was exposed to...could be passed to my kid. Did I just poison my kid?” *Anonymous PBB Registry member*
- Earlier puberty among daughters, increased risk of urinary and genital problems among sons.
 - “My daughter had her first menstrual period when she was five years old.” *Anonymous PBB Registry participant*

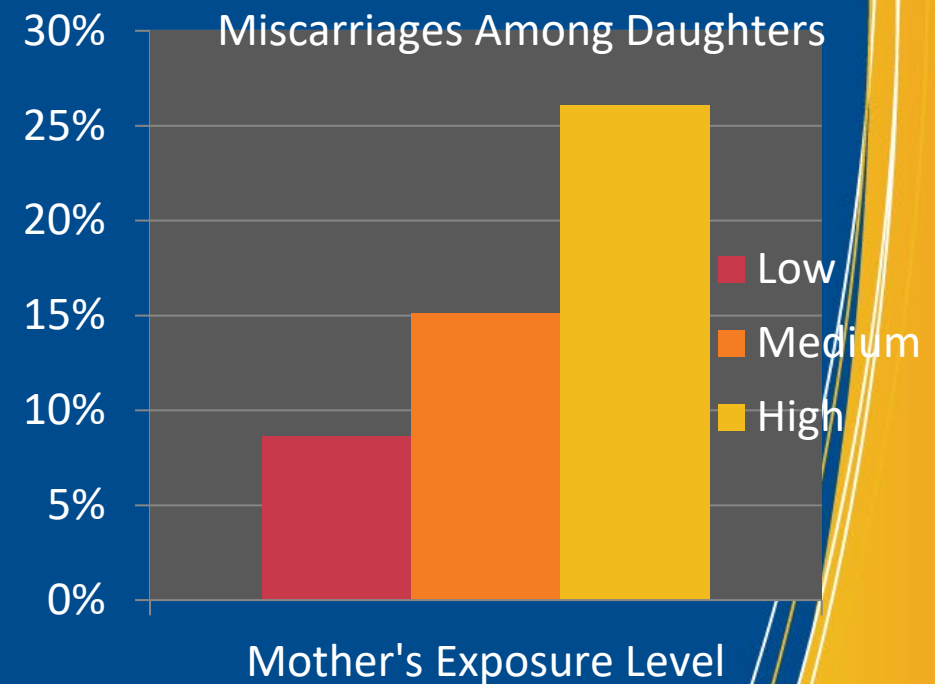


Additional Research Findings

- Increased risk of Thyroid Problems

“I had symptoms for years before my doctors considered thyroid problems as the cause. My years of suffering could have been avoided if the doctors knew my PBB level and the associated risks.” *Anonymous PBB Registry participant*

- Increased risk of Breast Cancer
- Three generations affected
- Extremely persistent in the body
 - 60% of Michiganders recently tested still had elevated levels of PBB in their blood
- Epigenetics



Community-Driven Research

“It was my father who was exposed. We are seeing the same health problems”

- Three-generation epigenetic study

“How can I get rid of the PBB in my body?”

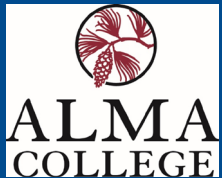
- Randomized trial of nutritional intervention to speed elimination of PBBs and other POPs

“My doctor doesn’t know anything about PBB”

- CME for health care providers and local public health

PBB Partnerships

Pre-Pandemic: in-person and remote



PBB Community Engagement
Monthly conference calls:
PBB Leadership Team



Quarterly conference calls:
PBB Citizens Advisory Board



PBB Partner Retreats 2x/yr:
All Partners



Community meetings: 4x/yr:
All Registry Members invited

Virtual

A VIRTUAL PBB COMMUNITY MEETING

A discussion about the health findings of the Michigan PBB Registry

Join us

Tuesday, September 22
6:30-8:30 PM EST
or
Saturday, September 26
9:30-11:30 AM EST

Connect with us live at:
www.facebook.com/PBBRegistry/live/

- Learn about ongoing PBB research
- Hear updates and stories from the PBB Oral History Project
- Interact with a panel of our community partners

Multiple Ways to Join

1

Watch, Listen and Chat



Type in the link provided and login to a Facebook account

2

Watch and Listen



Type in the link provided, even if you don't have a Facebook account

3

Listen



Call: (312) 626-6799
Meeting ID: 937 5367 1424

4

Watch, Listen and Chat



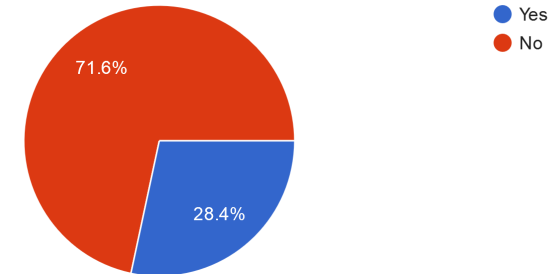
Join via Zoom:
<https://zoom.us/j/93753671424>

If you join via #2 or #3 above and cannot chat, please submit questions during the meeting by email:
pbbregistry@emory.edu



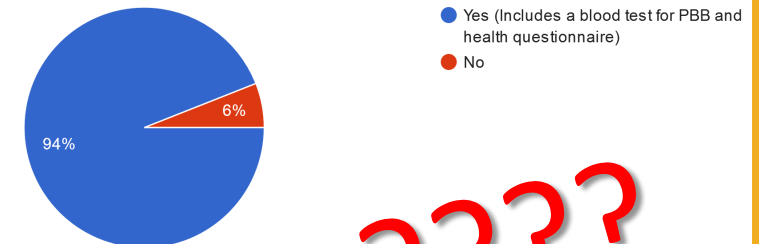
Have you attended a PBB community meeting before the recent virtual meetings?

201 responses



If eligible, are you interested in participating in PBB health studies?

184 responses



????

COVID Challenges

March 2020: University halts research activities



INTERRUPTED
&
ONGOING DELAYS

The Michigan PBB Registry

Save the Date
PBB Community Discussions
May 2nd and 3rd

May 2nd in St. Johns
May 3rd in Grand Rapids

More details coming soon!



RESEARCH
RECRUITMENT

Emory University invites you to participate in a
PBB Weight Loss Study

What's involved?

- Low-fat diet
 - Easy exercise
 - Weight loss pill
 - Blood tests for PBB levels
- \$100 compensation for 6 months of participation

This study may speed elimination of PBB from the body

3-MONTH Appointments
(Many in April & May)

Shelter-in-Place

- Self-measurements
- No Blood Collection

COMMUNITY PARTNERS TO THE RESCUE!!!

THESE APPOINTMENTS

Challenge: How do we collect blood samples and measurements on research participants while protecting the safety of the participants and the partner researchers?



Offers use of their facilities



Emory provides PPE for partner researchers



Research participants text upon arrival, wait in car for temperature check



Emory hires local phlebotomist



Only one participant admitted at a time. Allows for cleaning between participants.

Challenge: How do we maintain the integrity of the research data using partner researchers?



Partner researchers complete research ethics training and are added to Emory's IRB

Logo credit:
<https://about.citiprogram.org/en/homepage/>



Partner researchers trained on obtaining measurements and collecting blood specimens

Detailed written protocols clearly define the requirements for labeling, spinning, packing and transporting specimens



Emory provides packets with the required forms, specimen tubes and labels for each participant

Alma College students transport the blood samples to the Fed Ex Office

Community engagement/partnerships are the key to our projects' success



PBB Partner Retreat February 2020

- Community partners provide input on the appointment site locations
- Community partners provide input on the appointment/meeting dates
- Research participants are very dedicated to the project
- Community partners disseminate information through local communication channels



PBB Partner Retreat – February 2020

Mid-Michigan District Health Department
St. Johns, Michigan