

THE MICHIGAN PBB REGISTRY

AN INFORMATICS DRIVEN EXPOSURE REGISTRY

The Michigan PBB Registry
PBBRegistry.Emory.edu
1-888-892-0074
PBBRegistry@Emory.edu

NEW!

Community Discussion
March 8: 10am-noon & 2pm-4pm
March 9: 2pm-4pm

Blood Draw
March 7-16: 8am-7pm

Study Appointments
Are you 18-57 years old?
Please call 1-888-892-0074 to make an appointment for March 7-16

We are coming to Ithaca!
Join us at:
Mid-Michigan District Health Department
151 Commerce Drive
Ithaca, MI 48847

EMORY

PARTNERING FOR RESEARCH DRIVING PUBLIC HEALTH ACTION



Emory University



Michigan PBB Citizens Advisory Board

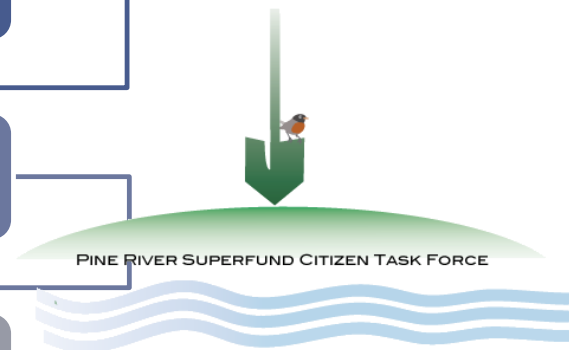
Mid Michigan District Health Department

Pine River Superfund Citizen Task Force

Alma College



Michigan PBB
Citizens Advisory Board





In 1931 the Michigan Chemical Corporation (Velsicol) was founded in St. Louis, Michigan. It later manufactured DDT, Poly Brominated Biphenyl (PBB) and other substances. In 1973 MCC accidentally shipped PBB, a toxic flame retardant, to a livestock feed plant operated by the Farm Bureau, instead of a nutritional supplement. It took about a year to understand what had happened. The breakthrough came when farmer Rick Halbert fed some of his animals Farm Bureau feed while withholding it from others. He saw that only the Farm Bureau fed animals got sick.



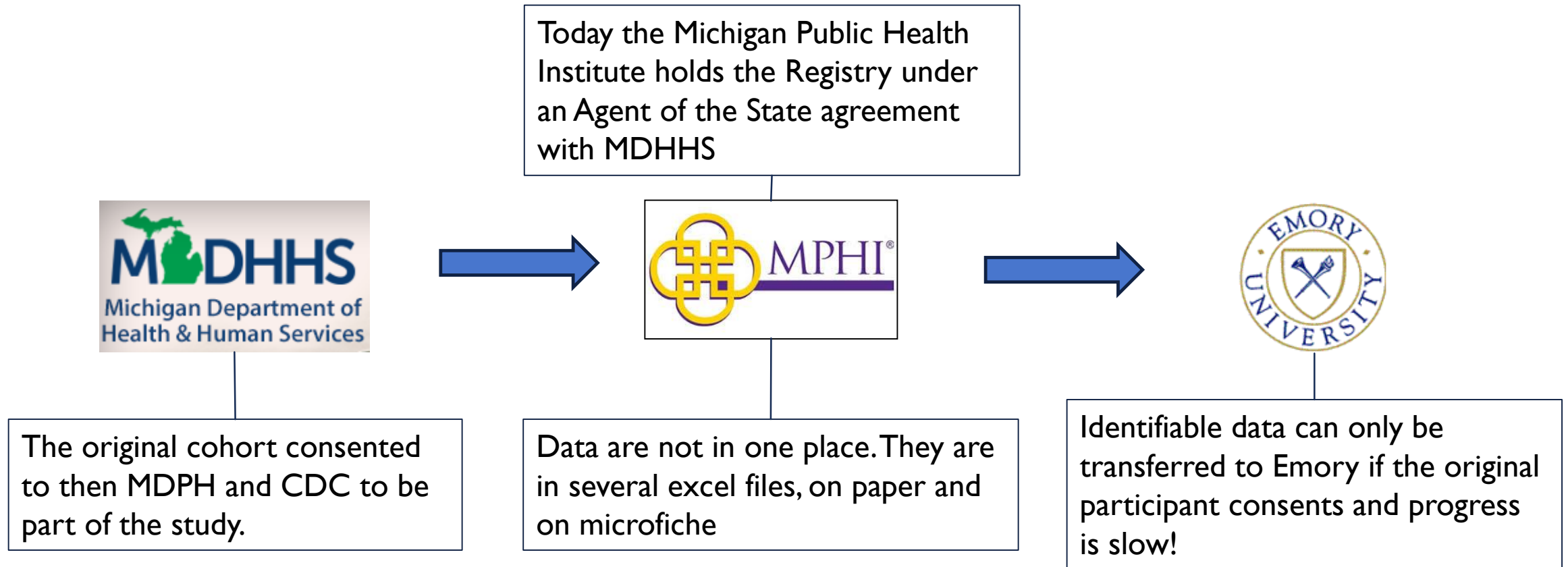
By that time, most Michigan cattle, pigs and chickens had consumed feed contaminated with PBB. Anyone in Michigan who ate beef, pork, eggs or milk was exposed to PBB. Thousands of animals had to be destroyed. Farm families who ate their own produce were exposed to even higher levels of PBB and became seriously ill. This was the largest food borne toxic exposure in American history. Chemical workers and their families also suffered a variety of exposures. Decades later Michiganders still have PBB levels 6 times higher than the national average. St. Louis groundwater was contaminated and the municipal wells had to be condemned. Two Superfund sites were established in St. Louis. Today the remediation of the plant site is just getting underway and many neighborhoods in St. Louis, MI., still have high levels of PBB and DTT in the soil.

THE PBB REGISTRY

A MODEL FOR PUBLIC HEALTH INFORMATICS

- The then MDPH had the foresight to create a long term study of the health effects of PBB.
- PBB is an example of a class of chemicals with epigenetic effects meaning subsequent generations can be affected even without exposure. These are proliferating in the environment and represent a significant public health threat.
- Ruth Etzel, Director of the Office of Children's Health Protection at US EPA described the Registry as “**a national treasure**”
- Community strongly supports continued research
- No systematic updates for over 25 years

CURRENT SITUATION



MSU gets \$14.4 million in federal funds for Flint lead exposure registry

3

Posted on August 1, 2017 at 1:16 PM



Michigan State University's College of Human Medicine is shown in this Flint Journal file photo.(Jake May | MLive.com)

**We've been here
before!**

MICHIGAN IS A LEADER IN PUBLIC HEALTH INFORMATICS

One of the first to implement National Electronic Disease Surveillance System (NEDSS) linking state and local health departments and other providers.

Syndromic surveillance system in use across the state for real time epidemiology and emergency preparedness

Successfully on-boarded eligible providers and hospitals for Meaningful Use.

The Medicaid database CareConnect 360 used by mental health providers for case management and population health assessment.

Statewide Health Information Exchanges in active use by providers and public health.

A pilot site for the Digital Bridge, national testing of electronic reporting of notifiable conditions

IMPORTANT TO THE COMMUNITY

Residents to be part of PBB health study

by Greg Nelson
Herald Editor

After more than a decade trying to get a health study regarding the ad-

He cited a major health assessment conducted last year called "Live Well Gratiot" that identified the effects of toxic chemicals among the "top health concerns."

Task force pleased to finally get health study

Posted on Tuesday, December 24th, 2013 and is filed under [News](#). You can follow any responses to this entry through the [RSS 2.0 feed](#). You can skip to the end and leave a response. Pinging is currently not allowed.

by Greg Nelson
Herald Editor

Researcher: PBB from 1970s still in Michiganders' blood

[Robin Erb](#), Detroit Free Press Published 11:51 p.m. ET Dec. 28, 2014 | Updated 11:52 p.m. ET Dec. 28, 2014



More than 200 get tested for PBB at St. Louis meetings

Posted on Wednesday, December 18th, 2013 and is filed under [FEATURE](#). You can follow any responses to this entry through the [RSS 2.0 feed](#). You can skip to the end and leave a response. Pinging is currently not allowed.



by Greg Nelson
Herald Editor

More than 200 people had blood withdrawn during two public meetings in St. Louis this past weekend in an effort to identify people who may have been exposed to PBB.

A VERY ACTIVE COMMUNITY

2014: Blood draws and community education

- Recruit new participants and gather new data on others. Nearly 1,000 participants.

2015: International conference on epigenetics

- Hosted by Alma college. Presenters from all over North America including EPA. Focus an environmental justice.

2017: Fund raisers for more blood testing

- 100s of people have applied to join the study or have more tests. After the previous grant expired no money to complete the tests.



IMPORTANT TO PUBLIC HEALTH PROFESSIONALS

View from the community and local public health

- Community members demand answers from us. They believe we can help them.
- We are aware of a significant public health problem but lack resources to deal with it.

Translating research to applied Public Health and Clinical Medicine to best care for patients

- Cancer screening; thyroid screening; newborn screening.
- Surveillance of the extent and magnitude of exposures.
- Need to advise physicians on best practices in exposed populations



ADVERSE HEALTH OUTCOMES ASSOCIATED WITH PBB

Small N studies have already show PBB is associated with adverse health outcomes.

Directly Exposed

- Male chemical plant workers more likely to be hypothyroid than controls.
- Higher PBB exposure associated with increased thyroid conditions among women.
- Higher PBB exposure associated with lower estrogen levels among women
- Higher PBB associated with higher risks of breast cancer, lymphoma and gastrointestinal cancers.

Children of directly exposed

PBB can cross the placenta and is concentrated in breast milk.

- Higher maternal PBB associated with lower Apgar scores at birth.
- Higher maternal PBB and breastfeeding associated with earlier menarche among daughters
- Higher maternal PBB associated with increased risk of miscarriages among daughters
- Higher maternal PBB associated with increased risk of genitourinary conditions among sons

PUBLIC HEALTH INFORMATICS IMPORTANT TO THE PEOPLE OF MICHIGAN



Community wants data to be used

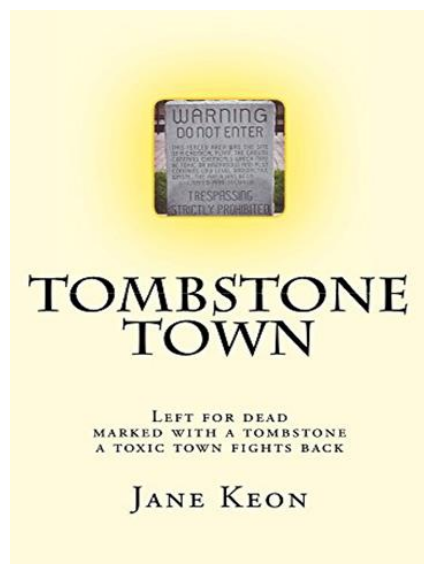
Ability to explore community's concerns

Testing self-reported symptoms against medical records

Discovery and recognizing patterns – alternate ways of understanding existing data (co-morbidities, effects)

Current research is driven by Community Priorities

- Based on years of collaboration/community engagement
 - Explore ways to speed elimination of PBBs
 - Explore epigenetic mechanism for health effects in future generations
 - Explore health concerns of the community
 - Provide training in environmental health to public health practitioners, clinicians and community



ADDITIONAL HEALTH CONCERNS OF THE COMMUNITY



Neurodevelopmental Conditions

- ADHD, learning disabilities, etc.

Degenerative diseases

- Alzheimer's, Parkinson's, Dementia, etc.

Joint Problems

- Atypical arthritis, joint replacement failure

Autoimmune diseases



RESEARCH APPLICATIONS OF AN INFORMATICS DRIVEN PBB REGISTRY

Cancer

- Linkage of PBB records for all registry members to National Cancer Registry data to provide more stable estimates of cancer incidence (e.g. Liver, Testicular)

Thyroid problems

- Newborn thyroid screening data can be used to identify trends over time related to the PBB contamination as well as identify geographic hotspots

Other Health concerns

- Linkage of PBB records for all registry members to Health Information Exchanges to explore other health concerns of community (e.g. developmental disorders, atypical arthritis, cognitive decline)

COMMUNITY FUNCTIONS OF AN INFORMATICS DRIVEN PBB REGISTRY

Public Health

- Identify trends over time related to the PBB contamination as well as identify geographic hotspots
- Access to exposure levels allows targeted screenings
- Can provide services to local community relevant to their needs

Individuals

- Can access their own records
- Help individuals proactively prepare for potential health impacts

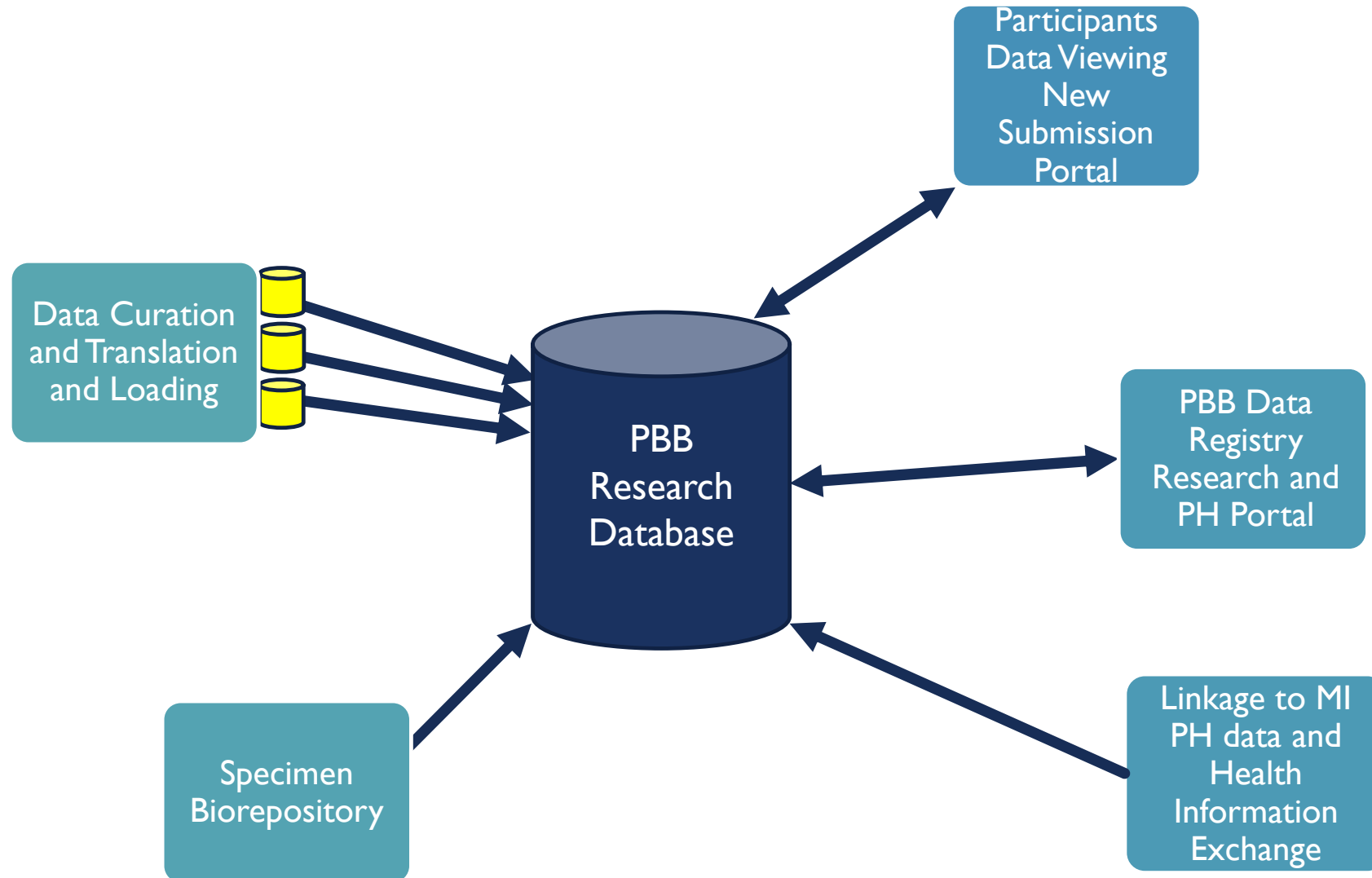
Clinicians

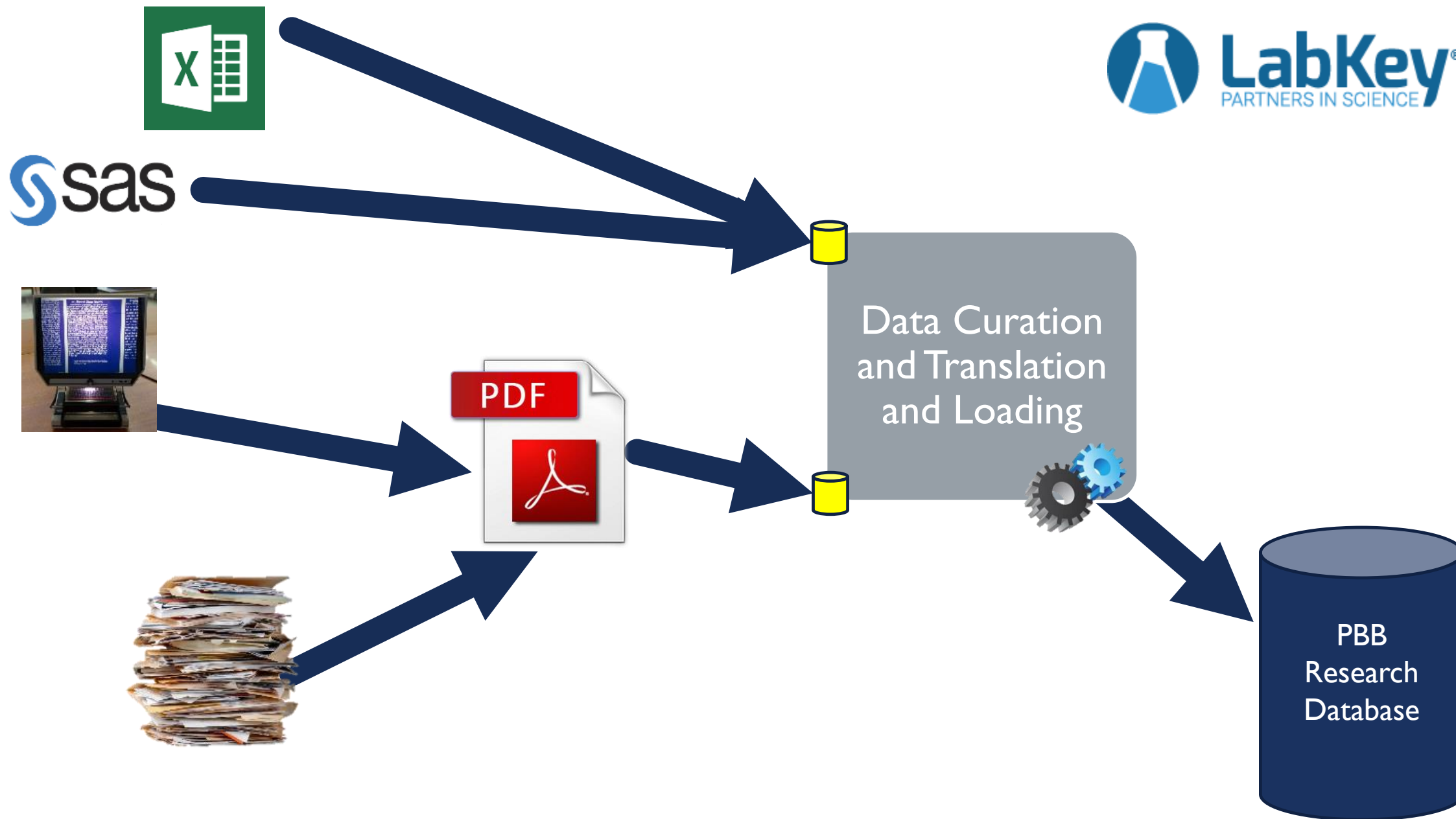
- Can access PBB exposure levels
- Research translation and information for patients



Location	Electronic Datasets	Paper Record/Microfiche
MDHHS	<ul style="list-style-type: none"> PBB Registry dataset (farm families & consumers of farm products only; n~5300) PBB Registry dataset (chemical workers/families; n~500; corrected dataset for sex and DOB) Other datasets – Needs to be determined 	<ul style="list-style-type: none"> Needs to be determined
MPHI	<ul style="list-style-type: none"> “Eligible” subset of PBB Registry dataset in 2009 (farm families/residents; n~4500) PBB Registry dataset of chemical workers & household members in 2014 (n~500; incorrect gender and DOB) 	<ul style="list-style-type: none"> Needs to be determined
Emory	<ul style="list-style-type: none"> De-identified PBB Registry dataset (farm families & consumers of farm products PLUS chemical workers; n~6800) More than 50 datasets of exposure data, questionnaires, measurements, physical exams, medical records, birth/offspring records, cancer registry data, death certificate data, family relationships, on various subsets of the population involved in Emory research 	<ul style="list-style-type: none"> Paper records of n ~ 3000 Microfiche n ~ 6,000 cards

The Michigan PBB Research Registry Resource Sharing Infrastructure





MOVING FORWARD

Expediting Transfer of Data

- Original cohort also consented to CDC
- Is CDC willing to hold the data?

NIH Proposal for cohort funding

- **IMMEDIATE NEEDS**
 - Inventory of all datasets
 - Strong letter of support from MDHHS
 - Renew Agent of the State agreement with MPHI or Emory



PBB LEADERSHIP TEAM



Jane-Ann Nyerges, Pat Muldoon

Jane Keon, Jim Hall, Gary Smith



Ed Lorenz, Christy Calhoun

Marcus Cheatham, Norm Keon, Lisa Mikesell, Dr. Jennifer Morse



Dr. Michele Marcus, Mark Conde, Metrecia Terrell, Melanie Pearson, Hillary Barton

THE END

