Alaska Area Specimen Bank A Unique Tribal-Federal Partnership

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Alaska Indigenous Research Program

Brenna Simons PhD, Director

imd4@cdc.gov or aasb@cdc.gov

What is a BIOREPOSITORY?





Secure Investment Bank





Evidence for clinical and epidemiological investigations



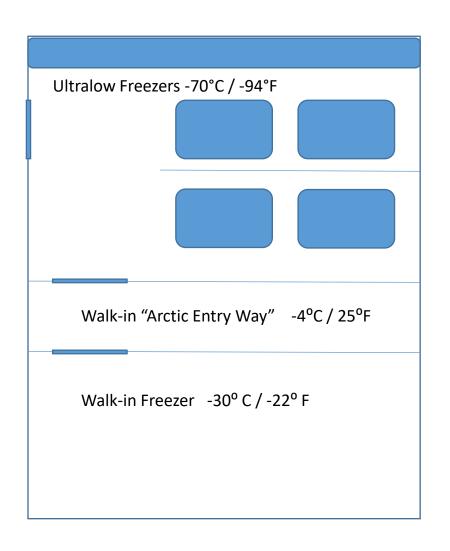
Tool Kit for development of treatments and preventions

What does a BIOREPOSITORY do?



What does a BIOREPOSITORY look like?

AASB at CDC Arctic Investigations Program



	Aliquots	Specimen	People
Total	618,170	343,332	104,508
Specimen	010,110	010,002	101,000
Types			
Serum	508977	277789	84404
Plasma	9131	6287	3378
Urine	2015	1212	1036
Cord	1805	1238	1233
blood			
NP/OP	26184	26010	10725
swabs			
DNA	11653	10714	6985
Bacterial	50518	33501	21138
cultures			
Other*	5342	4044	2017

^{*}Other includes: body fluids, tissues, white blood cells and whole blood

AASB at CDC Arctic Investigations Program







- Human genetic material
- Whole blood
- **Tissues**
- Bacterial cultures
- ➤ (Nose) Nasopharyngeal swabs
- > (Throat) Oropharyngeal swabs

CRYOVIALS BOX/RACK Organization Labeling



- > Serum
- Plasma
- Urine
- Whole Blood
- **Bacterial DNA**



How the AASB came to be

1958

Serum samples collected and kept by Arctic Research Center

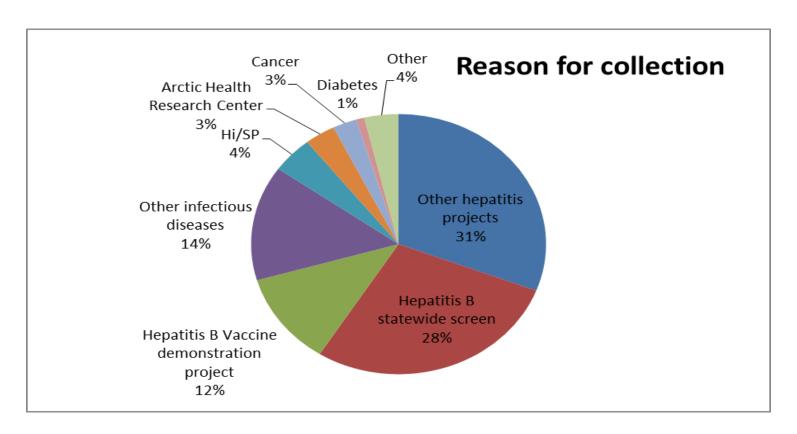
1980-1990

Serum samples collected by State of Alaska/THO/CDC For Hepatitis B Statewide Surveillance and Vaccine Cohorts Stored and maintained by CDC AIP

1998

CDC AIP moves to Alaska Native Health Campus – transfers sample collections to the physical AASB established at AIP facility.

(AASB) Original Reason for Collection



>85% Alaska Native or American Indian

> The remaining 15% are Alaskan.

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Collaboration: CDC AIP, State of Alaska, and Tribal leadership. Establish the Specimen Collections as a Biorepository, as a Resource.

Working Group is created to develop a policy for the AASB and for co-management.

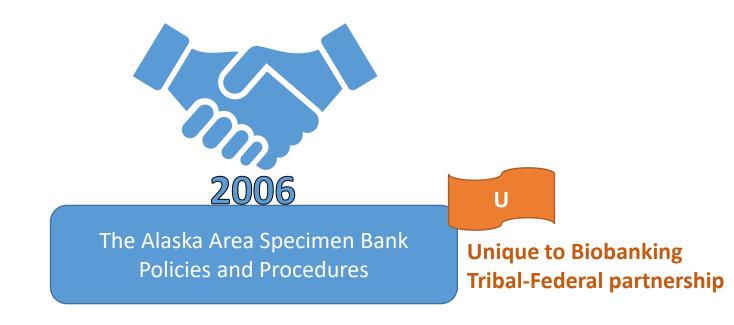


How the AASB came to be

1998-2006

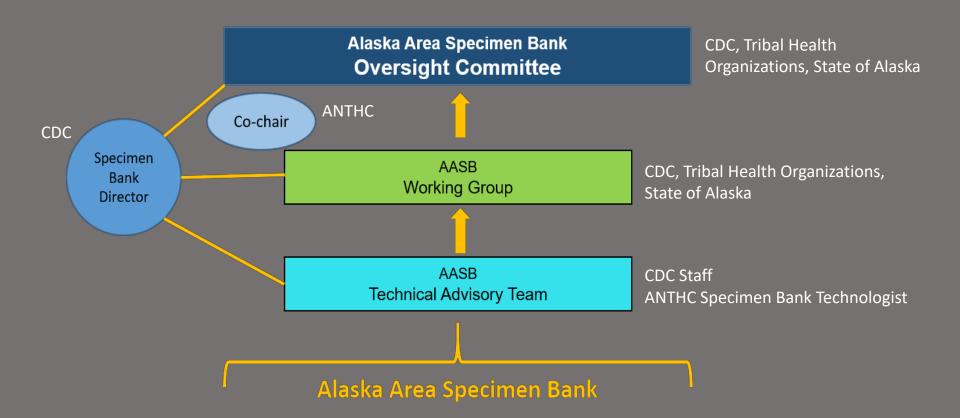
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Co-Management of the AASB

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Alaska Area Specimen Bank (AASB) Policy The Foundation

AASB is considered a resource for improving the health and well-being of all Alaskans, but with special emphasis on Alaska Native and American Indian persons.

Individual specimens contained within the bank remain the property of the individuals who consented to have their specimens stored for future research use.



ALASKA AREA SPECIMEN BANK

Why store specimens?

Specimens in the bank can provide a way to learn about the health of Alaska Native people over time. What is learned could help improve lives.

Where did the specimens come from?

The specimens are from research studies, outbreaks and medical procedures. Most of the specimens are from Alaska Native people. The bank has been saving specimens since the 1960s. Most specimens were collected to learn about infectious diseases like hepatitis.

How are specimens stored?

Specimens are stored in small tubes and kept frozen. The tubes are labeled with a number linked to a person's name and birthdate. Specimens are stored safely in special freezers with limited access.

Who manages the Alaska Area Specimen Bank?

The AASB Oversight Committee manages the bank. This group is made up of representatives from Alaska Native Tribal Health Consortium (ANTHC), Centers for Disease Control and Prevention (CDC), and Alaska Native Tribal Health Organizations (THO).

How can a researcher or other individual get permission to use specimens?

Specimens contained within the bank are the property of the individuals who consented to have their specimens stored. Future tests on these specimens which use your name or other identifiers will not be done without consent.

Any future testing which will not use your name or personal identifiers will only be done with the approval of the Alaska Area Institutional Review Board, your THO and ANTHC when ANTHC staff/facilities are involved, or the ANMC health records are accessed.

Alaska Area Specimen Bank's mission makes sure human specimens:

- Are secured in storage facilities for future use
- Are used to address health concerns of Alaska Native people
- Are used in a way that respects Tribal Health and Federal guidelines which protect people's confidentiality, moral values and involvement in research studies

Specimen: a sample of blood, tissue or body fluid from human beings which can be used for testing or research.

"The AASB is used to conduct research and remains a carefully managed resource to improve the health of the Alaska Native people.... Over time, research, data ownership, informed consent, and individual specimen's ownership have been determined by the Alaska Native people. That is an example of how partnerships by the right mix of organizations, federal and tribal, produce an operational system that engages the Alaska Native community in the process of managing a specimen bank."

H. Sally Smith Alaska Native Tribal Health Leader

Centers for Disease Control and Prevention, Arctic Investigations Program

1055 Tudor Centre Drive, Anchorage, AK 99508 907) 729-3400 | (800) 699-0767 | aasb@cdc.gov

Adapting the AASB from Past to Present

2006

The Alaska Area Specimen Bank Policies and Procedures

- New developments in biorepository science and innovation
- Genetics Research
- Individualized Medicine
- Upgrades to biospecimen handling, automation and data security
- Evolving federal laws and regulations (i.e. OHRP/ Final Rule
- Tribal Sovereignty and growing capacity

2021

Revising the AASB Policy

Step 1

Identify & Review Best Practices

Step 2

• Identify Key Elements

Step 3

Evaluate Current AASB Policy with Key Elements

Step 4

Incorporate New and Update Existing (Draft)

Step 5

- Review and Discuss with Tribal-Federal Partnership
- Stakeholder Focus Groups, Open forums
- THE AASB POLICY SUMMIT

Thank you





Biorepository Best Practices Resources List

- American Indian and Alaska Native Genetics Resource Guide: Tools for Tribal Leaders and Citizens
- International Society for Biological and Environmental Repositories—4th Edition (ISBER)
- National Cancer Institute (NCI) Best Practices for Biospecimen Resources
- U.S. Centers for Disease Control and Prevention (CDC) Sample Management Policy
- Code of Federal Regulations (CFR) 2019 'Final Rule' updates to Institutional Review Board policy