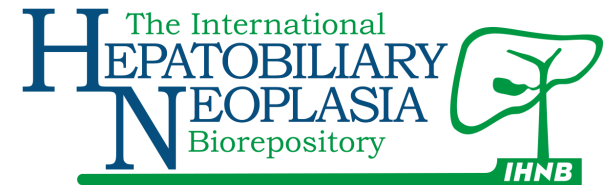


About Us

The International Hepatobiliary Neoplasia Registry and Biorepository (IHNB) is a collaboration between Mayo Clinic, The Cholangiocarcinoma Foundation, and multiple academic medical centers. The registry and biorepository are a resource for researchers, patients, and families.



Participating Institutions

Mayo Clinic: Arizona

Principal Investigator: Dr. Mitesh Borad

Mayo Clinic: Jacksonville

Principal Investigator: Dr. Tushar Patel

Mayo Clinic: Rochester

Principal Investigator: Dr. Lewis Roberts

Liver Associates of Texas

Principal Investigator: Dr. Victor Ankoma-Sey

ProMedica Flower Hospital

Principle Investigator: Dr. Kerri Simo

University of Calgary

Principle Investigator: Dr. Oliver Bathe

University of California, San Francisco (UCSF)

Principal Investigator: Dr. R. Kate Kelly

Virginia Piper Cancer Inst., Allina Health System

Principal Investigator: Dr. Srinevas Reddy

Contact Us

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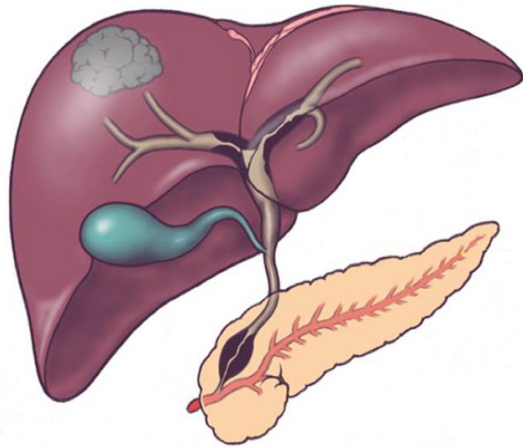
Collaborative Projects

The biorepository and registry is undertaking the following projects:

- The NCI Cancer Genome Atlas (TCGA) Projects for Hepatocellular Carcinoma and Cholangiocarcinoma
- Hepatocellular Carcinoma Genome-Wide Association Study (GWAS) with MD Anderson Cancer Center, Dartmouth University, and the NCI Hepatocellular Carcinoma Epidemiology Consortium
- Cholangiocarcinoma GWAS with MD Anderson Cancer Center, Dartmouth University, and other collaborators
- Individual collaborations with investigators on specific protocols



**Improving Care for
 People with Liver and
 Biliary Cancers**



Purpose

1. To maintain a registry of persons having or at risk for hepatobiliary cancers, including family members of patients
2. To develop a resource (bank) of biospecimens (blood, tissue, bile, stool, and urine) to:
 - Facilitate studies on the pathogenesis of hepatobiliary cancers
 - Assess the utility of new biomarkers to detect early cancer

Diagnosis	Blood	Tissue	Blood + Tissue	Bile	Stool
CCA	531	25	88	37	18
HCC	407	71	93	0	20
Mixed HCC/CCA	14	0	5	0	0
Gallbladder Cancer	53	4	6	0	0
Cirrhosis	192	2	3	0	0
Other	408	47	42	0	2
PSC	56	0	2	43	0
Total	1,661	149	239	82	40

International Hepatobiliary Neoplasia Registry and Biorepository (IHNB) Summary as of July 31, 2014

Background

Cholangiocarcinoma (CCA), cancer of the bile ducts, is the second most common hepatobiliary cancer, affecting about 16,000 people in the United States each year. Most CCAs arise in individuals without any risk factors. Incidence rates of intrahepatic Cholangiocarcinoma have risen substantially in the US, Japan, Australia and Europe over the last 30 years. The reason for this phenomenon is unclear.

Hepatocellular Carcinoma (HCC) is the sixth most common cancer and the second most frequent cause of cancer death worldwide.

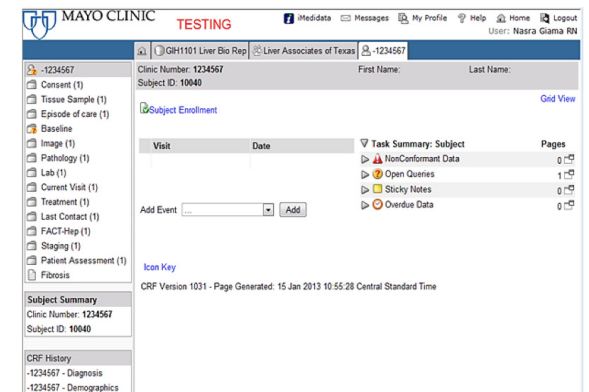
Gallbladder carcinoma affects about 7,000 people per year in the United States.

It is important to improve our understanding of the risk factors for development of these cancers. Because the poor prognosis of these cancers is usually due to late diagnosis, there is also an urgent need for biomarkers with improved sensitivity for the detection of these cancers and also for novel therapeutics to improve outcomes of patients with hepatobiliary cancers.

3. To administer a risk factor questionnaire to facilitate identification of risk factors for development of hepatobiliary cancer
4. To obtain germline blood DNA to allow future analysis of genotypes conferring risk for development of hepatobiliary cancer
5. To develop patient-derived xenografts and immortalized cell-lines from resected or biopsied specimens to allow studies to determine the optimal targeted therapy or chemotherapy for each tumor
6. To develop prognostic models for survival of patients from time of diagnosis

International Hepatobiliary Neoplasia Registry and Biorepository (IHNB)

- De-identified data entered in a centralized registry to promote collaboration
- Data is entered in case report forms on a HIPAA-compliant, iMedidata-RAVE database developed and maintained by the study team and statisticians at the Mayo Clinic under an IRB-approved protocol
- Each collaborating site has access to their own data upon request
- Individual site Primary Investigators participate as members of a steering committee to guide study development



iMedidata Rave: A centralized data bank