Find a Registry

CGA is pleased to offer members access to a vast list of global registries.
The list below provides you with quick access to Registries throughout the US, Canada and South America.

Need assistance in contacting a registry?

For information on starting a registry, please contact CGA at info@cgaigc.com

If you are interested in more information on starting a hereditary colorectal cancer registry, a manual is available online to members.

(password required)

Registry Manual Available for Download Soon

Argentina

Caba

Programa de Cáncer Hereditario del Hospital Italiano de BsAs (Pro.Can.He)
Principal Investigator: Walter Pavicic
Coordinator Name: Fabiana Alejandra Ferro
Registry Phone: +54 11 4959 0200
Registry Email Address: procanhe@hospitalitaliano.org.ar
Registry Website: https://www1.hospitalitaliano.org.ar/#!/home/procanhe/seccion/9841
Recruitment Status: Active, Open to patients who present for at least one visit, Participation can be done remotely
Consortium: Prospective Lynch Syndrome Database (PLSD)
Pediatric Patients: No
Hereditary Cancer Syndromes Included: Lynch Syndrome (MLH1, MSH2, MSH6, PMS2 & EPCAM), Other Non-Polyposis Families (FCCTX, Amsterdam II), Familial Adenomatous Polyposis (APC), Attenuated Familial Adenomatous Polyposis (APC), MUTYH-Associated Polyposis (MUTYH), Polymerase Proofreading-Associated Polyposis (POLE & POLD1), Peutz-Jeghers Syndrome (including STK11), Juvenile Polyposis Syndrome (including BMPR1A & SMAD4), PTEN Tumor Hamartoma Syndrome (PTEN), Hyperplastic Polyposis/Serrated Polyposis (including RNF43), Other Polyposis Syndromes (Mixed, GREM1, NTHL1, MSH3)
Data Collection Software: Microsoft Access

Cordoba

Hospital Privado (HP)
Principal Investigator: Claudia Martin
Coordinator Name: Claudia Martin
Registry Phone: +54 35 1559 0424
Registry Email Address: claudia.martin81@gmail.com
Registry Website: www.hospitalprivado.com.ar
Recruitment Status: Closed, Limited to patients seen at the participating institution
Consortium: EORC-LATAM
Pediatric Patients: Yes
Hereditary Cancer Syndromes Included: Lynch Syndrome (MLH1, MSH2, MSH6, PMS2 & EPCAM), Constitutional Mismatch Repair Deficiency (MLH1, MSH2, MSH6, PMS2 & EPCAM), Other Non-Polyposis Families (FCCTX, Amsterdam II), Familial Adenomatous Polyposis (APC), Attenuated Familial Adenomatous Polyposis (APC), Peutz-Jeghers Syndrome (including STK11), Hereditary Diffuse Gastric Cancer (including CDH1 & CTNNA1)
Data Collection Software: Excel

Brazil

Sao Paulo

Registro de Câncer Hereditário do Hospital Beneficência Portuguesa de São Paulo (RCHBP)
Principal Investigator: Benedito Mauro Rossi
Coordinator Name: Erika Maria Monteiro Santos
Registry Phone: +55 11 3705 6735
Registry Email Address: oncogenetica@bp.org.br
Registry Website: https://www.bp.org.br/centros-de-especialidades/oncologia
Recruitment Status: Active, Open to patients who present for at least one visit
Consortium: Colorectal Cancer in Latin America
Pediatric Patients: No
Hereditary Cancer Syndromes Included: Lynch Syndrome (MLH1, MSH2, MSH6, PMS2 & EPCAM), Other Non-Polyposis Families (FCCTX, Amsterdam II), Familial Adenomatous Polyposis (APC), Attenuated Familial Adenomatous Polyposis (APC), MUTYH-Associated Polyposis (MUTYH), PTEN Tumor Hamartoma Syndrome (PTEN), Hyperplastic Polyposis/Serrated Polyposis (including RNF43), Hereditary Diffuse Gastric Cancer (including CDH1 & CTNNA1), Familial/Hereditary Pancreatic Cancer,
Data Collection Software: Progeny and RedCap

Canada

Ontario

Familial GI Cancer Registry/Zane Cohen Centre for Digestive Diseases (FGICR)
Principal Investigator: Zane Cohen
Coordinator Name: Melyssa Aronson
Registry Phone: +1 (416) 586-4800 ext. 3154
Registry Email Address: melyssa.aronson@sinaihealth.ca
Registry Website: https://www.zanecohencentre.com/fgicr
Recruitment Status: Active, Participation can be done remotely
Consortium: Pancreatic Cancer Genetic Epidemiology Consortium (PACGENE), Pancreatic Cancer Case-Control (PANC4) Consortium, International Mismatch Repair Consortium (IMRC), Colon Cancer Family Registry (CCFR or Colon CFR), Prospective Lynch Syndrome Database (PLSD)
Hereditary Cancer Syndromes Included: Lynch Syndrome (MLH1, MSH2, MSH6, PMS2 & EPCAM), Constitutional Mismatch Repair Deficiency (MLH1, MSH2, MSH6, PMS2 & EPCAM), Other Non-Polyposis Families (FCCTX, Amsterdam II), Familial Adenomatous Polyposis (APC), Attenuated Familial Adenomatous Polyposis (APC), MUTYH-Associated Polyposis (MUTYH), Polymerase Proofreading-Associated Polyposis (POLE & POLD1), Peutz-Jeghers Syndrome (including STK11), Juvenile Polyposis Syndrome (including BMPR1A & SMAD4), Other Polyposis Syndromes (Mixed, GREM1, NTHL1, MSH3), Hereditary Diffuse Gastric Cancer (including CDH1 & CTNNA1), Familial/Hereditary Pancreatic Cancer
Data Collection Software: Microsoft Access

International

Genetics of Colonic Polyposis (GCPS)

Principal Investigator: Daniel Buchanan
Coordinator Name: Sharelle Joseland
Registry Phone: +61 385 597 004
Registry Email Address: daniel.buchanan@unimelb.edu.au
Registry Website: http://www.buchananlab.org/
Recruitment Status: Active, Participation can be done remotely
Consortium: Colon Cancer Family Registry (CCFR or Colon CFR)
Pediatric Patients: No
Data Collection Software: Microsoft Access

Colon Cancer Family Registry Cohort (CCFR)
Principal Investigator: Mark A. Jenkins
Coordinator Name: Allyson Templeton
Registry Phone: +1 (206)667-6313
Registry Email Address: atemplet@fredhutch.org
Registry Website: www.coloncfr.org
Recruitment Status: Closed, Participation can be done remotely
Consortium: Colon Cancer Family Registry (CCFR or Colon CFR)
Pediatric Patients: No
Data Collection Software: Site-Specific

Bowel Cancer Surveillance Service
Principal Investigator: Finlay A Macrae
Coordinator Name: Finlay A Macrae
Registry Phone: +61 3 8559 7232
Registry Email Address: finlay.macrae@mh.org.au
Recruitment Status: Active, Participation can be done remotely
Consortium: International Mismatch Repair Consortium (IMRC), Colon Cancer Family Registry (CCFR or Colon CFR), Prospective Lynch Syndrome Database (PLSD)
Hereditary Cancer Syndromes Included: Lynch Syndrome (MLH1, MSH2, MSH6, PMS2 & EPCAM), Constitutional Mismatch Repair Deficiency (MLH1, MSH2, MSH6, PMS2 & EPCAM), Other Non-Polyposis Families (FCCTX, Amsterdam II), Familial Adenomatous Polyposis (APC), Attenuated Familial Adenomatous Polyposis (APC), MUTYH-Associated Polyposis (MUTYH), Polymerase Proofreading-Associated Polyposis (POLE & POLD1), Peutz-Jeghers Syndrome (including STK11), Juvenile Polyposis Syndrome (including BMPR1A & SMAD4), PTEN Tumor Hamartoma Syndrome (PTEN), Hyperplastic Polyposis/Serrated Polyposis (including RNF43), Other Polyposis Syndromes (Mixed, GREM1, NTHL1, MSH3), Lower/moderate colorectal cancer risk genes

USA

California

Hereditary GI Cancer Prevention Registry
Principal Investigator: Aparajita Singh
Coordinator Name: Laurel Hochstetler
Registry Phone: +1 (415) 885-7481
Registry Email Address: laurel.hochstetler@ucsf.edu
Registry Website: https://kintalk.org
Recruitment Status: Active, Participation can be done remotely
Hereditary Cancer Syndromes Included: Lynch Syndrome (MLH1, MSH2, MSH6, PMS2 & EPCAM), Constitutional Mismatch Repair Deficiency (MLH1, MSH2, MSH6, PMS2 & EPCAM), Other Non-Polyposis Families (FCCTX, Amsterdam II), Familial Adenomatous Polyposis (APC), Attenuated Familial Adenomatous Polyposis (APC), MUTYH-Associated Polyposis (MUTYH), Polymerase Proofreading-Associated Polyposis (POLE & POLD1), Peutz-Jeghers Syndrome (including STK11), Juvenile Polyposis Syndrome (including BMPR1A & SMAD4), PTEN Tumor Hamartoma Syndrome (PTEN), Hyperplastic Polyposis/Serrated Polyposis (including RNF43), Other Polyposis Syndromes (Mixed, GREM1, NTHL1, MSH3), Hereditary Diffuse Gastric Cancer (including CDH1 & CTNNA1), Familial/Hereditary Pancreatic Cancer, Lower/moderate colorectal cancer risk genes
Data Collection Software: Progeny, FIlemaker Database

Connecticut

Smilow Cancer Genetics and Prevention Program Research Repository
Principal Investigator: Xavier Llor

Coordinator Name: Xavier Llor
Registry Phone: +1 (203) 200-4362
Registry Email Address: xavier.llor@yale.edu
Recruitment Status: Active, Open to patients who present for at least one visit
Consortium: International Cancer of the Pancreas Screening (CAPS) Consortium
Hereditary Cancer Syndromes Included: Lynch Syndrome (MLH1, MSH2, MSH6, PMS2 & EPCAM), Constitutional Mismatch Repair Deficiency (MLH1, MSH2, MSH6, PMS2 & EPCAM), Other Non-Polyposis Families (FCCTX, Amsterdam II), Familial Adenomatous Polyposis (APC), Attenuated Familial Adenomatous Polyposis (APC), MUTYH-Associated Polyposis (MUTYH), Polymerase Proofreading-Associated Polyposis (POLE & POLD1), Peutz-Jeghers Syndrome (including STK11), Juvenile Polyposis Syndrome (including BMPR1A & SMAD4), PTEN Tumor Hamartoma Syndrome (PTEN), Hyperplastic Polyposis/Serrated Polyposis (including RNF43), Other Polyposis Syndromes (Mixed, GREM1, NTHL1, MSH3), Hereditary Diffuse Gastric Cancer (including CDH1 & CTNNA1), Familial/Hereditary Pancreatic Cancer, Lower/moderate colorectal cancer risk genes
Data Collection Software: Progeny

Illinois

Sandra Rosenberg Registry for Hereditary and Familial Colon Cancer
Principal Investigator: Joshua Melson, MD
Coordinator Name: Sandra Valdez
Registry Phone: (312)942-5861
Registry Email Address: joshua_melson@rush.edu
Registry Website: https://www.rush.edu/locations/high-risk-gi-cancer-clinic
Recruitment Status: Active, Limited to patients seen at the participating institution, Open to patients who present for at least one visit
Consortium: Prospective Lynch Syndrome Database (PLSD)
Pediatric Patients: No
Hereditary Cancer Syndromes Included: Lynch Syndrome (MLH1, MSH2, MSH6, PMS2 & EPCAM), Familial Adenomatous Polyposis (APC), Attenuated Familial Adenomatous Polyposis (APC), MUTYH-Associated Polyposis (MUTYH), Peutz-Jeghers Syndrome (including STK11), Juvenile Polyposis Syndrome (including BMPR1A & SMAD4), PTEN Tumor Hamartoma Syndrome (PTEN), Hyperplastic Polyposis/Serrated Polyposis (including RNF43), Familial/Hereditary Pancreatic Cancer
Data Collection Software: Redcap

Missouri

Washington University Inherited Colorectal Cancer and Familial Polyposis Registry (WashU ICCFPR)
Principal Investigator: Paul E. Wise
Registry Phone: (314)454-7177
Registry Website: https://siteman.wustl.edu/treatment/cancer-types/colorectal/inherited-colorectal-cancer-and-familial-polyposis-registry/
Recruitment Status: On Hold, Open to patients who present for at least one visit
Consortium: International Mismatch Repair Consortium (IMRC), Prospective Lynch Syndrome Database (PLSD)
Pediatric Patients: Yes
Hereditary Cancer Syndromes Included: Lynch Syndrome (MLH1, MSH2, MSH6, PMS2 & EPCAM), Other Non-Polyposis Families (FCCTX, Amsterdam II), Familial Adenomatous Polyposis (APC), Attenuated Familial Adenomatous Polyposis (APC), MUTYH-Associated Polyposis (MUTYH), Polymerase Proofreading-Associated Polyposis (POLE & POLD1), Peutz-Jeghers Syndrome (including STK11), Juvenile Polyposis Syndrome (including BMPR1A & SMAD4), PTEN Tumor Hamartoma Syndrome (PTEN), Hyperplastic Polyposis/Serrated Polyposis (including RNF43),
Data Collection Software: Excel

New York

Clinical Hereditary GI Cancers Registry
Principal Investigator: Francesca Tubito
Coordinator Name: Francesca Tubito
Registry Phone: +1 (877) 902-2232
Registry Email Address: FRT2004@med.cornell.edu
Registry Website: https://www.nyp.org/cadc/support-wellness/clinical-hereditary-gi-cancers-registry
Recruitment Status: Active, Open to patients who present for at least one visit

Hereditary Cancer Syndromes Included: Lynch Syndrome (MLH1, MSH2, MSH6, PMS2 & EPCAM), Constitutional Mismatch Repair Deficiency (MLH1, MSH2, MSH6, PMS2 & EPCAM), Other Non-Polyposis Families (FCCTX, Amsterdam II), Familial Adenomatous Polyposis (APC), Attenuated Familial Adenomatous Polyposis (APC), MUTYH-Associated Polyposis (MUTYH), Polymerase Proofreading-Associated Polyposis (POLE & POLD1), Peutz-Jeghers Syndrome (including STK11), Juvenile Polyposis Syndrome (including BMPR1A & SMAD4), PTEN Tumor Hamartoma Syndrome (PTEN), Hyperplastic Polyposis/Serrated Polyposis (including RNF43), Other Polyposis Syndromes (Mixed, GREM1, NTHL1, MSH3), Hereditary Diffuse Gastric Cancer (including CDH1 & CTNNA1), Familial/Hereditary Pancreatic Cancer, Lower/moderate colorectal cancer risk genes

Adherence to Comprehensive Multi-Organ Screening Recommendations in Patients with Lynch Syndrome
Principal Investigator: Zsofia K. Stadler
Coordinator Name: Zsofia K. Stadler
Registry Phone: +1 (646) 888-4039
Recruitment Status: Active, Participation can be done remotely
Hereditary Cancer Syndromes Included: Lynch Syndrome (MLH1, MSH2, MSH6, PMS2 & EPCAM), Constitutional Mismatch Repair Deficiency (MLH1, MSH2, MSH6, PMS2 & EPCAM)
Data Collection Software: Excel, Progeny

Ohio

Hereditary Polyposis Clinic at Nationwide Children's
Principal Investigator: Steve Erdman
Coordinator Name: Steve Erdman
Registry Phone: +1 01 61 4722 3411
Registry Email Address: steven.erdman@nationwidechildrens.org
Registry Website: https://www.nationwidechildrens.org/specialties/polyposis-services
Recruitment Status: Active, Participation can be done remotely
Consortium: International Mismatch Repair Consortium (IMRC), Colon Cancer Family Registry (CCFR or Colon CFR)
Hereditary Cancer Syndromes Included: Lynch Syndrome (MLH1, MSH2, MSH6, PMS2 & EPCAM), Constitutional Mismatch Repair Deficiency (MLH1, MSH2, MSH6, PMS2 & EPCAM), Familial Adenomatous Polyposis (APC), Attenuated Familial Adenomatous Polyposis (APC), MUTYH-Associated Polyposis (MUTYH), Polymerase Proofreading-Associated Polyposis (POLE & POLD1), Peutz-Jeghers Syndrome (including STK11), Juvenile Polyposis Syndrome (including BMPR1A & SMAD4), PTEN Tumor Hamartoma Syndrome (PTEN), Hyperplastic Polyposis/Serrated Polyposis (including RNF43), Other Polyposis Syndromes (Mixed, GREM1, NTHL1, MSH3), Hereditary Diffuse Gastric Cancer (including CDH1 & CTNNA1)

The Ohio State University Population-Based Colorectal Cancer Cohorts (OSU CRC Cohorts)
Principal Investigator: Heather Hampel
Coordinator Name: Heather Hampel
Registry Phone: +1(614) 293-7240
Registry Email Address: Heather.Hampel@osumc.edu
Registry Website: https://cancer.osu.edu/for-patients-and-caregivers/learn-about-cancers-and-treatments/innovation-at-the-james/genetic-counseling
Recruitment Status: Closed, Limited to patients seen at the participating institution
Consortium: International Mismatch Repair Consortium (IMRC), Genetics and Epidemiology of Colorectal Cancer Consortium (GECCO)
Pediatric Patients: No
Hereditary Cancer Syndromes Included: Lynch Syndrome (MLH1, MSH2, MSH6, PMS2 & EPCAM), Constitutional Mismatch Repair Deficiency (MLH1, MSH2, MSH6, PMS2 & EPCAM), Other Non-Polyposis Families (FCCTX, Amsterdam II), Familial Adenomatous Polyposis (APC), Attenuated Familial Adenomatous Polyposis (APC), MUTYH-Associated Polyposis (MUTYH), Polymerase Proofreading-Associated Polyposis (POLE & POLD1), Peutz-Jeghers Syndrome (including STK11), Juvenile Polyposis Syndrome (including BMPR1A & SMAD4), PTEN Tumor Hamartoma Syndrome (PTEN), Hyperplastic Polyposis/Serrated Polyposis (including RNF43), Other Polyposis Syndromes (Mixed, GREM1, NTHL1, MSH3), Hereditary Diffuse Gastric Cancer (including CDH1 & CTNNA1), Familial/Hereditary Pancreatic Cancer
Data Collection Software: RedCa

Pennsylvania

Hereditary Colorectal and Associated Tumor Study
Principal Investigator: Randall Brand
Coordinator Name: Randall Brand
Registry Phone: +1 (412) 623-3105
Registry Email Address: brandre@upmc.edu
Recruitment Status: Active, Limited to patients seen at the participating institution
Consortium:
Hereditary Cancer Syndromes Included: Lynch Syndrome (MLH1, MSH2, MSH6, PMS2 & EPCAM), Other Non-Polyposis Families (FCCTX, Amsterdam II), Familial Adenomatous Polyposis (APC), Attenuated Familial Adenomatous Polyposis (APC), MUTYH-Associated Polyposis (MUTYH), Polymerase Proofreading-Associated Polyposis (POLE & POLD1), Peutz-Jeghers Syndrome (including STK11), Juvenile Polyposis Syndrome (including BMPR1A & SMAD4), PTEN Tumor Hamartoma Syndrome (PTEN), Hyperplastic Polyposis/Serrated Polyposis (including RNF43), Other Polyposis Syndromes (Mixed, GREM1, NTHL1, MSH3), Hereditary Diffuse Gastric Cancer (including CDH1 & CTNNA1), Lower/moderate colorectal cancer genes
Data Collection Software: Open Specimen

The Pancreatic Adenocarcinoma Gene Environment Risk Study (PAGER)
Principal Investigator: Randall Brand
Coordinator Name: Randall Brand
Registry Phone: +1 (412) 623-3105
Registry Email Address: brandre@upmc.edu
Registry Website: https://clinicaltrials.gov/ct2/show/NCT00912717
Recruitment Status: Active, Limited to patients seen at the participating institution
Consortium: International Cancer of the Pancreas Screening (CAPS) Consortium, The Cancer of the Pancreas Screening-5 Study (CAPS5), Pancreatic Cancer Early Detection Consortium (PRECEDE)
Hereditary Cancer Syndromes Included: Familial/Hereditary Pancreatic Cancer
Data Collection Software: Open Specimen

Tennessee

Inherited Cancer Registry (ICARE)
Principal Investigator: Tuya Pal
Coordinator Name: Anne Weidner
Registry Phone: (615)875-2444
Registry Email Address: ICARE@inheritedcancer.net
Registry Website: https://inheritedcancer.net/
Recruitment Status: Active, Participation can be done remotely
Pediatric Patients: No
Hereditary Cancer Syndromes Included: Lynch Syndrome (MLH1, MSH2, MSH6, PMS2 & EPCAM), Other Non-Polyposis Families (FCCTX, Amsterdam II), Attenuated Familial Adenomatous Polyposis (APC), Polymerase Proofreading-Associated Polyposis (POLE & POLD1), Juvenile Polyposis Syndrome (including BMPR1A & SMAD4), Hyperplastic Polyposis/Serrated Polyposis (including RNF43), Hereditary Diffuse Gastric Cancer (including CDH1 & CTNNA1)
Data Collection Software: RedCap

Utah

Hereditary Gastrointestinal Cancer Registry (HGCR)
Principal Investigator: Deb Neklason
Coordinator Name: Megan Keener
Registry Phone: +1(801) 585-6439
Registry Email Address: registry.coordinator@hci.utah.edu
Registry Website: https://healthcare.utah.edu/huntsmancancerinstitute/screening-prevention/hereditary-gastrointestinal-cancers-registry.php
Recruitment Status: Active, Participation can be done remotely
Consortium: International Mismatch Repair Consortium (IMRC)
Pediatric Patients: Yes
Hereditary Cancer Syndromes Included: Lynch Syndrome (MLH1, MSH2, MSH6, PMS2 & EPCAM), Constitutional Mismatch Repair Deficiency (MLH1, MSH2, MSH6, PMS2 & EPCAM), Other Non-Polyposis Families (FCCTX, Amsterdam II), Familial Adenomatous Polyposis (APC), Attenuated Familial Adenomatous Polyposis (APC), MUTYH-Associated Polyposis (MUTYH), Polymerase Proofreading-Associated Polyposis (POLE & POLD1), Peutz-Jeghers Syndrome (including STK11), Juvenile Polyposis Syndrome (including BMPR1A & SMAD4), PTEN Tumor Hamartoma Syndrome

(PTEN), Hyperplastic Polyposis/Serrated Polyposis (including RNF43), Other Polyposis Syndromes (Mixed, GREM1, NTHL1, MSH3), Hereditary Diffuse Gastric Cancer (including CDH1 & CTNNA1), Familial/Hereditary Pancreatic Cancer, Lower/moderate colorectal cancer risk genes
Data Collection Software: Internal Database

Patient-Lead

The HEROIC Registry
Principal Investigator: Robin Dubin
Coordinator Name: Robin Dubin
Registry Phone: +1 (201) 694-8282
Registry Email Address: robin@aliveandkickn.org
Registry Website: https://www.aliveandkickn.org/the-heroic-patient-registry
Recruitment Status: Active, Participation can be done remotely
Consortium: LunaDNA Platform
Pediatric Patients: No
Hereditary Cancer Syndromes Included: Lynch Syndrome (MLH1, MSH2, MSH6, PMS2 & EPCAM)
Data Collection Software: LunaDNA Platform