

People to Contact With Questions

Many individuals helped in the development of this guide. The list of individuals below includes contributing authors as well as other individuals who are willing to answer questions about genetics research in American Indian/Alaska Native communities:

Puneet Chawla Sahota, PhD is the Senior Research Fellow at the National Congress of American Indians Policy Research Center. Dr. Sahota led the project to develop this web-based genetics research resource guide and served as editor for the website. She has worked with the National Congress of American Indians since 2006, and has written papers on a number of health issues important to tribal nations, including health care reform, suicide prevention, community-based participatory research, and tribal research regulation. In 2009, Dr. Sahota earned her PhD in anthropology. Her dissertation examined the relationship between an American Indian community and medical/genetics research, including ethical, political, and cultural issues. For her dissertation, Dr. Sahota spent two years conducting ethnographic fieldwork with a tribal community in the Southwest. She helped the tribe develop its own policies on research regulation, and she also conducted in-depth interviews with community members on their views of medical/genetics research. Dr. Sahota is also an MD candidate at Washington University in St. Louis. She can be reached at puneet.sahota@yahoo.com.

Malia Villegas (Sugpiaq/Alutiiq), EdD, is Alaska Native with family from Kodiak and Afognak Islands in Alaska and O'ahu and Lana'i in Hawai'i. She is an enrolled member of the Native Village of Afognak in Alaska and serves as the Director of the NCAI Policy Research Center, where she leads projects on public health, research regulation and design, and data mapping. Dr. Villegas completed her doctorate in Culture, Communities, and Education at the Harvard Graduate School of Education. She recently completed a Post-Doctoral Fellowship at the Queensland University of Technology in Brisbane, Australia, as part of a team evaluating the first, national, longitudinal Indigenous education initiative since the 2008 Apology to the Stolen Generations -- the Stronger Smarter Learning Communities Project that seeks to improve the leadership culture of schools serving Indigenous Australians. Dr. Villegas is committed to improving the educational experiences of Indigenous and rural youth and communities by exploring innovative institutional partnerships and community-based research processes. Her specific research interests include Indigenous philosophies of education, community- and place-based education, sovereignty and data development, and comparative Indigenous research. In 2008, Dr. Villegas traveled on a Fulbright Fellowship to Aotearoa (New Zealand) to explore the successful Maori higher education initiative to develop 500 Maori PhDs in five years, which became the subject of her dissertation. Dr. Villegas has also served as a Research Fellow for the Alaska Native Policy Center of First Alaskans Institute, where she worked on research and policy related to Alaska Native education, student success, and community development. In 2008, she co-edited a volume (with S. R. Neugebauer & K. R. Venegas) entitled, *Indigenous Knowledge & Education: Sites of Struggle, Strength, and Survivance*. Malia completed her undergraduate studies in Political Science and Ethnic Studies at Stanford University and received an Ed. M. in Education Policy and Management from the Harvard Graduate School of Education. She can be reached at mvillegas@ncai.org.

Christina Daulton, MA is Program Manager at the National Congress of American Indians Policy Research Center and managed the project to develop this web-based genetics research resource guide for American Indian/Alaska Native communities. Ms. Daulton joined the Policy Research Center in August 2008. For the past ten years, she has been a researcher and policy analyst on higher education issues, mainly focusing on access and equity issues, including the contributions of tribal colleges and universities to their communities. Prior to joining NCAI, Ms. Daulton worked for the

Institute for Higher Education Policy and the National Association of College and University Business Officers. She brings strong research skills from both her academic training and work experience, and has written a number of publications for both organizational members and policymakers to use as tools for advocacy and program development. Ms. Daulton supports a number of Policy Research Center projects and works directly with tribal leaders and their communities in providing the data and tools needed to empower their communities in shaping their own future. She is originally from Passaic, New Jersey, and earned a Bachelor's degree in English Education from the University of Delaware and a Master's degree in American Studies from The George Washington University. She can be reached at cdaulton@ncai.org.

Vence L. Bonham, JD is the Chief of the Education and Community Involvement Branch (ECIB) at the National Human Genome Research Institute (NHGRI), National Institutes of Health which leads the Institute's public education and community involvement and outreach initiatives. He is also an associate investigator in the Social and Behavioral Research Branch, Division of Intramural Research, National Human Genome Research Institute, National Institutes of Health. Mr. Bonham's research and scholarship is at the intersection of law, public policy, health care and genetics. His research focuses primarily on the social influence of new genomic knowledge, particularly in communities of color. Mr. Bonham is interested in how genomic discoveries influence social identity, how genomics might influence the use of the constructs of race and ethnicity in biomedical research, and the role of genetics and genomics in understanding racial and ethnic health disparities. Prior to joining the National Institutes of Health, Mr. Bonham was an Associate Professor (*with tenure*) at Michigan State University, East Lansing, Michigan in the Colleges of Medicine and Law. He can be reached at bonhamv@mail.nih.gov.

Native American Cancer Initiatives, Incorporated is a for-profit company founded in 1998 (based in Colorado) to provide technical assistance to communities, patients, researchers, academicians, universities, research institutions, and professionals on Native Americans, cultural issues, program development and assessment and the full continuum of cancer (prevention through end-of-life care). NACI developed "Genetic Education for Native Americans" (GENA®) [PI: Burhansstipanov, HG01866]. GENA provides a Native-specific science curriculum comprised of 29 objectives. These objectives can be individually combined to create an educational program on genetic science that is tailored to a group's specific needs. The focus of GENA is to help workshop participants increase their genetic knowledge to assist with informed decision-making regarding genetic science, testing, or research opportunities. The curriculum is neither "pro" nor "con" genetic science, but rather presents potential benefits, risks, and/or drawbacks. The NACI website is <http://www.natamcancerinitiatives.org/> and the phone number is 303-838-9359.

Victoria Warren-Mears, PhD, RD is the Director of The EpiCenter at the Northwest Portland Area Indian Health Board. As Director, she has the specific responsibility of managing The EpiCenter and developing processes to measure the progress of northwest Indian health programs toward meeting the health status objectives of the Indian Health Care Improvement Act. She completed her doctoral program in Nutrition Science at the University of Washington, where she focused on nutrition, public health and medical ethics. She completed post-doctoral training in Human Investigations at Oregon Health & Science University. She is experienced in conducting population based research and programmatic implementation. Dr. Warren-Mears has experience collaborating with the Northwest tribal communities and personal contacts within tribal organizations, IHS and other federal agencies. She may be reached at vwarrenmears@npaihb.org.

Náníbaa' A. Garrison (Navajo), PhD, is a postdoctoral research fellow at the Center for Integration of Research on Genetics & Ethics at Stanford University. Her current research interests include ethical, legal, social and cultural issues in genetic research that include indigenous issues in genetic research, personal genomics, and issues with privacy, confidentiality, and informed consent.

Nánibaa' earned her Ph.D. in Genetics at Stanford University. Her research was on the genetics of human pigmentation. Nánibaa' is from Kayenta, AZ and graduated from the University of Arizona in 2003 with a BS in Molecular & Cellular Biology. She may be reached at nanibaa@stanford.edu.

Jessica Bardill (Cherokee), PhD is currently a Chancellor's Postdoctoral Fellow in American Indian Studies at the University of Illinois, Urbana-Champaign, and serves on the Advisory Board of the Summer Internship for Native Americans in Genomics (SING) Workshop. While at Duke University, she produced a dissertation that engages science, law, and stories to understand identity and belonging in Indian Country, entitled "Beyond Blood and Belonging: Alternarratives for a Global Citizenry." Jessi has also worked with the Genome Ethics, Law, & Policy Center of Duke's Institute for Genome Sciences and Policy. She is of Cherokee, Irish, Scottish, and Swiss heritages from Tennessee, and a proud MMUF (Mellon-Mays Undergraduate Fellowship) Fellow. She can be reached at jessi.bardill@gmail.com.

Lee Bitsóí (Diné), EdD, currently serves as a Research Associate in the Department of Molecular and Cellular Biology where he assists with the Diversity Action Plan for the FlyBase Training Program. In addition, Dr. Bitsóí is the lead Native American scholar for an initiative focusing on men of color sponsored by the College Board. As an advocate for minority scientists and scholars, Dr. Bitsóí also serves as the Secretary for the Board of Directors for the Society for Advancement of Chicanos/Latinos and Native Americans in Science. Dr. Bitsóí previously served as the Minority Action Plan (MAP) Program Director in the Department of Genetics at Harvard Medical School, where he directed a recruitment plan for underrepresented minority students interested in pursuing genomic sciences at the undergraduate and post-doc levels. He has also served as a Research Assistant Professor in the Department of Human Science at Georgetown University, and Director of Minority Training in Bioinformatics & Genomics at Harvard University. In addition, he has worked at Dartmouth College and San Juan College, and as an Education Strategy Consultant for the Institute for Higher Education Policy in Washington, DC. Dr. Bitsóí has devoted his career to enhancing opportunities for under-represented minority students to become scientists, science educators and scientifically-informed community members. Dr. Bitsóí earned a bachelor of science degree with honors from the University of New Mexico (1995), where he was initiated into the prestigious Phi Beta Kappa Honor Society. He holds a master of education degree from Harvard University (1998) where he was initiated into another prestigious honor society—Phi Delta Kappa. Dr. Bitsóí earned a doctorate from the University of Pennsylvania (2007) where his research focused on the conditions that encourage and discourage American Indians from pursuing higher education, a subject upon which he has published. Dr. Bitsóí can be contacted at bitsoi@fas.harvard.edu.

Wylie Burke, MD, PhD, is Professor and Chair of the Department of Bioethics and Humanities at the University of Washington. She received a PhD in Genetics and an MD from the University of Washington, where she completed a residency in Internal Medicine and was a Medical Genetics Fellow. She is the director of the University of Washington Center for Genomics and Healthcare Equality, which focuses on partnership-based research to address the ethical and policy implications of genetics in research and health care. She may be reached at wburke@u.washington.edu.

Rosalina (Rose) James (Lummi), PhD is Acting Assistant Professor in the Department of Bioethics and Humanities at University of Washington. Rose currently directs the Indigenous Genomics Alliance and Training cores for the Center for Genomics and Healthcare Equality and teaches an undergraduate course on Responsible Conduct of Research. She also co-chairs the Advancing Indigenous Research Ethics in Practice and Policy, a committee exploring successful models for tribal-university research agreements. Rose is an enrolled member of the Lummi tribe and a Duwamish descendent. She may be reached at rdjames@u.washington.edu.

Brett Lee Shelton (Oglala Lakota), JD, has worked extensively in the United States and

internationally working with tribes and tribal peoples addressing issues of research and colonization. He has published model tribal research codes, and his law firm is available to help with many related legal issues, such as research regulation by tribes, review or drafting of research agreements and sample storage agreements. He works at the law firm of Smith, Shelton & Ragona in Westminster, CO, and can be reached at (303) 255-3588.

Rosita Worl (Tlingit), PhD serves as President of the Sealaska Heritage Institute and as a professor of anthropology at the University of Alaska Southeast. She is the Vice Chair of the Board of Directors of Sealaska Corporation and a member of the Board of Directors of the Alaska Federation of Natives. At the national level, she serves on the board of trustees of the Smithsonian National Museum of American Indians and chair of the Native American Graves Protection and Repatriation Act Review Committee. Dr. Worl is a Tlingit and member of the Thunderbird Clan from the House Lowered from the Sun and a Child of the Sockeye Clan. Dr. Worl has done extensive research throughout the Alaska and the circumpolar Arctic and has served on the National Science Foundation Arctic Program Committee, the National Science Committee overseeing the social scientific studies of the Exxon Valdez Oil Spill, the Scientific Committee of the Arctic Eskimo Whaling Commission and science advisor to the International Whaling Commission in 1979. She has written a number of landmark studies and reports on bowhead whale and seal hunting, impacts of industrial development on Native communities, repatriation, and Tlingit real and intellectual property laws. She may be reached at rosita.worl@sealaska.com.

David R. Wilson (Diné), PhD is from Northern New Mexico. He graduated with a PhD in molecular and cellular biology from Arizona State University in 2006. He began encouraging underrepresented minorities to pursue careers in science at High Schools and Community Colleges in the four corners area. In 2010 Dr. Wilson completed a 3 year post-doc and was promoted to a Senior Research Scientist position at the National Institutes of Health in the National Institute on Ageing in the Laboratories of Molecular and Cellular Biology under the direction of Dr. Sebastian Fugmann. His research focused in two major areas: the evolutionary origins of the enzymes Recombination Activating Genes 1 and 2 which are essential in the development and maturation of functional immunoglobulins. Secondly he studied the epigenetic regulatory functions of the histone deacetylase Sirtuin 6. As a research scientist at the NIA he was actively involved in recruiting underrepresented minorities from the southwest to experience research opportunities at the NIH. Currently as a member of the SACNAS organization Dr. Wilson is initiating strategies to create and implement more Native American programs across the country while strengthening existing ones. He can be reached at dave@sacnas.org or dr.wilson89@gmail.com.

Jean McEwen, JD, PhD is a Program Director in the Ethical, Legal, and Social Implications Program in the Extramural Division of the National Human Genome Research Institute, where she manages a portfolio of grants focused on societal issues in genetics and genomics research. She is also responsible for administrative oversight of the bioethics components of several major NHGRI and NIH genomics research initiatives, including the 1000 Genomes Project and the Human Microbiome Project (HMP) (a trans-NIH Roadmap Initiative), and she oversaw all of the informed consent, community consultation, and sample collection processes for the International HapMap Project. Dr. McEwen has developed and managed a number of research initiatives, including RFAs relating to the return of genomic research results and the ethical, legal, and social implications of human genetic variation research, and managed consortia of NHGRI-funded investigators conducting research in these areas. Dr. McEwen has a B.A. in Philosophy from the University of Minnesota, a J.D. from Northwestern University Law School, and a Ph.D. in Social Policy from Brandeis University. She may be reached at jm522n@nih.gov.

Laura Lyman Rodriguez, PhD, is the Director for the Office of Policy, Communications, and Education and the Senior Advisor to the Director for Research Policy at the National Human

Genome Research Institute (NHGRI), National Institutes of Health (NIH). Dr. Rodriguez works to develop and implement policy for research initiatives at the NHGRI, as well as trans-NIH programs. She is particularly interested in the policy and ethics questions related to the inclusion of human research participants in genomics and genetics research. Among other activities, Dr. Rodriguez has provided leadership for many of the policy development activities pertaining to genomic data sharing and the creation of the database for Genotypes and Phenotypes (dbGaP) at the NIH. Dr. Rodriguez received her bachelor of science with honors in biology from Washington and Lee University in Virginia and earned a doctorate in cell biology from Baylor College of Medicine in Texas. She can be reached at rodrigla@mail.nih.gov.

Kim TallBear (Sisseton-Wahpeton Oyate), PhD is Assistant Professor of Science, Technology, and Environmental Policy at the University of California, Berkeley. She studies how genomics is co-constituted with ideas of race and indigeneity. Her book, *Native American DNA: Origins, Ethics, and Governance*, is forthcoming with the University of Minnesota Press. Her newest research is entitled: "Constituting Knowledge across Cultures of Expertise and Tradition: Indigenous Bio-scientists." She is interested in the role of Native American scientists in the democratization (and making more multi-cultural) of bio-scientific fields. She is also interested in their potential role in the development of scientific governance within tribes. Kim blogs and tweets on science, technology, and indigenous issues at www.kimtallbear.com. Kim is enrolled Sisseton-Wahpeton Oyate and is also descended from the Cheyenne & Arapaho Tribes of Oklahoma. She may be reached at kimberly.tallbear@berkeley.edu.

Francine C. Gachupin (Jemez Pueblo), PhD, MPH, CIP is Assistant Professor, Department of Family and Community Medicine, College of Medicine, University of Arizona, Tucson. Dr. Gachupin has extensive experience working with American Indian tribal communities focusing primarily on chronic disease surveillance, public health practice, epidemiology and research. Dr. Gachupin obtained her doctorate from the University of New Mexico and her Master of Public Health in Epidemiology from the University of Washington in Seattle. Her work has been based primarily at tribal epidemiology centers including northwest, northern plains, and southwest tribes. She has been PI to several projects focused on behavioral risk factors, cancer control, diet and nutrition, mortality, injury, and population genetics. Dr. Gachupin has served as co-Chair to the National IHS IRB and Chair of both the Portland Area IHS IRB and the Southwest Tribal IRB. She has served on the Secretary's Advisory Council for Human Research Protections (SACHRP), the Canadian Institutes of Health Research (CIHR) Institute for Aboriginal People's Health (IAPH) Institute Advisory Board (IAB), and on data safety monitoring boards for the Strong Heart Study (SHS) and Genetics of Coronary Artery Disease among Alaska Natives (GOCADAN) Study - both funded by the National Heart, Lung, and Blood Institute (NHLBI) - and the Adult Dental Caries (ADC) Project funded by the National Institute of Dental and Craniofacial Research (NIDCR). She can be reached at fcgachupin@email.arizona.edu.

William L. Freeman, MD, MPH, CIP is Program Director of the Northwest Indian College (NWIC) Center for Health, Director of Tribal Community Health Programs there, and Human Protections Administrator for the NWIC's Institutional Review Board (IRB). Bill retired from the Indian Health Service (IHS) in January 2002 after 25 years. In his first 13 IHS years, he was a family physician in the Lummi Tribal Health Center of the Lummi Nation. For his last 12 IHS years, he was director of the IHS research program and Chair of the IHS IRB. He promoted both community-based participatory research (CBPR) and tribal IRBs during that time. He is a member of the NWIC IRB, and of three other Tribal IRBs in the western US by conference call. His interests include: the ethics of research involving Native people and communities; the role of participants, their concerns, and their strong desires in genetic research; resiliency and strengths of Native people; CBPR; and (with both a personal and professional interest) the ethics and safety of living kidney donation. He can be reached at wfreeman@nwic.edu and WilliamLFreeman@att.net.

