Mountain States Genetics Network
Small Grant Program
"Public and Targeted Education in Genetics"
Final Report – August 28, 2007

When the grant application was originally written, our understanding was that it would cover a two year time frame and thus our objectives were written to encompass what we thought could be accomplished in that time. Using a portion of the funds originally allocated, we were able to make progress on two of the three objectives in our May 2006 revised application. We presented three open-invitation lectures and forums on topical subjects in genetics for the lay public, and initiated discussions with Native American communities regarding the possibilities of presenting public forums on genetics and genetic diseases. Staffing and time restrictions unfortunately prohibited the creation of the proposed website.

A speaker's committee was formed consisting of University of Arizona faculty members Drs. Kate Dixon, Professor and Head of Molecular and Cellular Biology; Michael Nachman, Professor, Ecology and Evolutionary Biology and Director, IGERT Program in Genomics; Vicki Chandler, Director - BIO5 Institute, Regents' Professor, Plant Sciences and Molecular & Cellular Biology; Michael Hammer, Research Scientist, Division of Biotechnology and Department of Ecology and Evolutionary Biology; Giovanni Bosco, Molecular and Cellular Biology; and Murray Brilliant, Chair, Graduate Interdisciplinary Program in Genetics, Lindholm Professor of Mammalian Genetics,
Department of Pediatrics. Acting on suggestions received, invitations were extended to:

Francis Collins, Director, National Human Genome Research Institute

David Botstein, Director, Lewis-Sigler Institute for Integrative Genomics, Princeton University

Douglas Wallace, Director, Center for Molecular & Mitochondrial Medicine and Genetics, UC Irvine School of Medicine

Phillip Reilly, M.D., J.D., Chief Executive Officer of Interleukin Genetics Incorporated

Eric Lander, Founding Director of the Broad Institute

Patricia Hunt, Ph.D. and Terry Hassold, Ph.D., Washington State University

Keith Cheng, M.D., Ph.D., Associate Professor of Pathology, Biochemistry and Molecular Biology, and Pharmacology; Jake Gittlen Cancer Research Foundation, Penn State College of Medicine

John M. Butler, Ph.D., Project Leader, Human Identity DNA Measurements Group, National Institute of Standards and Technology

Alfred G. Knudson, Jr., M.D., Ph.D., Senior Advisor to the President, Fox Chase Cancer Center

The last three speakers on the list were those who accepted our invitation. Their seminar fliers and evaluation results are presented on the following pages.

Each public lecture was advertising utilizing the following venues: "3D" memos to the University of Arizona community, distributed to any University of Arizona faculty/staff member who has asked to be placed on the 3D e-mail list; Calendar listings in the Tucson morning and evening newspapers; calendar listings in the AZ Daily Wildcat, the campus newspaper, and emails to relevant faculty mailing lists. For Drs. Butler's and Knudson's lectures, advertising was purchased on radio station KUAT, which aired a total of 20 spots over a one-week period for each lecture. In addition, a poster announcing Dr. Knudson's lecture was created for display in the clinical patient area of the Arizona Cancer Center and announcement was sent to the local chapter of the American Cancer Society.

Significant progress was made towards engaging the Navajo Nation in a Public Forum on Genetics. A team of advisors and co-sponsors was formed. Other people, of potential importance to the project, were added to our contact list and all were informed of our progress. This list includes: Michael Trujillo, Douglas Peter, John Hubbard, Daryl Melvin, Anselm Roanhorse, Ben Shelly, Alray Nelson, Roselyn Begay, John R. Lewis, Mark Bauer, Kathleen Rita DeLaRosa, Kristi Lawrence, Steve Holve, Trish Thomas, Leigh Kuwanwisiwma, Gene Humeyestewa, Vicki Chandler, Robert Valenzuela, Nanibaa' Garrison, Leslie J. Baier, Robert P. Erickson.

A plan was submitted to the Navajo Nation IRB and, on July 17, 2007, Dr. Brilliant met with the Navajo Nation IRB to discuss the proposed forum. A detailed proposal to the IRB is attached. Although the IRB did not wish to co-sponsor the educational forum, individual members saw merit in the proposal and stated that they would like to attend, albeit in their unofficial status.

Dr. Brilliant feels strongly that an official Navajo governmental or social agency must be a co-sponsor and partner in this effort. A discussion was initiated with Dr. Edward Garrison and Dr. Mark Bauer of Dine College, the official higher education entity of the Navajo Nation. Dr. Brilliant is to meet with these individuals at Window Rock on September 28, 2007.

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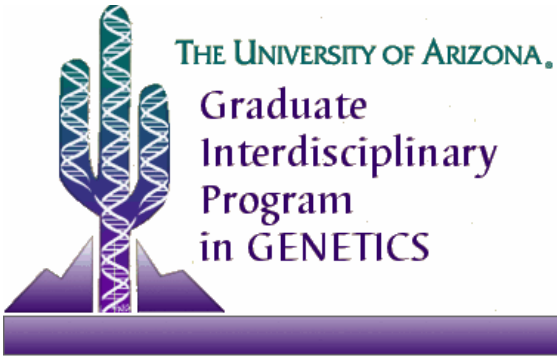


Sponsored by a grant from the Mountain States Genetics Network
Presents

Keith Cheng, M.D., Ph.D.
Associate Professor of Pathology, Biochemistry and Molecular Biology, and Pharmacology; Jake Gittlen Cancer Research Foundation
Penn State College of Medicine

Presenting a Public Education Seminar

"Surprising Insights into Human Skin Color from Zebrafish and Music"

Today - Friday, December 1, 2006
7:00 pm
Duval Auditorium, University Medical Center
1501 N. Campbell Ave.

In addition to his scientific talents, Dr. Cheng is a concert pianist. In conjunction with the portion of his talk dealing with the commonality of musical and scientific thinking, he will perform Rachmaninoff's "Vocalise" on the grand piano. Refreshments will be served and admission is free to the public.

Program Evaluation Results – Keith Cheng Public Education lecture 12/1/06:

Notes – A total of 14 evaluations were returned. On 2 evaluations only half the questions were responded to (i.e., they missed the back side). We printed 150 programs/evaluations, and 120 were leftover. However, the rough head count I took during the lecture indicated that attendance was closer to 50 people.

Did you enjoy tonight's presentation?
1 ….. 2 ….. 3 ….. 4 ….. 5 …..
(not at all) ……(very much)
Average = 4.77

Do you understand more about the field of genetics after this lecture?
1 ….. 2 ….. 3 ….. 4 ….. 5 …..
(no) …….. (a lot more)
Average = 4.0

Did the speaker seem knowledgeable about his subject?
1 ….. 2 ….. 3 ….. 4 ….. 5 …..
(no) ……(very knowledgeable)
Average = 4.92

Was the length of the talk appropriate?
1 ….. 2 ….. 3 ….. 4 ….. 5 …..
(too short)…….(too long)
Average = 3.31

Did the speaker adequately respond to questions from the audience?
1 ….. 2 ….. 3 ….. 4 ….. 5 …..
(no)……(yes, quite well)
Average = 4.7

How important do you believe it is for the general public to be educated about the field of genetics?
1 ….. 2 ….. 3 ….. 4 ….. 5 …..
(not important)...……....(essential)
Average = 4.61

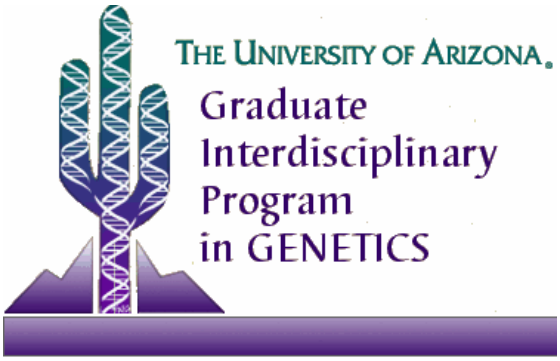
This presentation made me want to learn more about genetic research
1 ….. 2 ….. 3 ….. 4 ….. 5 …..
(not at all)……(very interested)
Average = 4.5

Was this location easy for you to reach?
1 ….. 2 ….. 3 ….. 4 ….. 5 …..
(no)……..…(yes)
Average = 4.46

How likely are you to attend a future lecture in this Genetics Education series?
1 ….. 2 ….. 3 ….. 4 ….. 5 …..
(not at all) ……...(definitely)
Average = 4.61

Please list any genetic-related topics about which you would like to learn more (i.e., genetic counseling, crime lab genetics, cancer treatment, etc.)
"all of the above", genetics disorders & testing, epistasis, cancer treatment, muscular distrophy

How did you hear about this lecture?
(list all that apply)
Email (3), personal communication, announcement, friend, EEB announcement, genetics class



Sponsored by a grant from the Mountain States Genetics Network
Presents

a Public Education Seminar

by

John M. Butler, Ph.D.

Project Leader, Human Identity DNA Measurements Group,
National Institute of Standards and Technology

"Beyond CSI: Exciting Applications of Forensic DNA"

Friday, March 9, 2007
7:00 pm
Duval Auditorium, University Medical Center
1501 N. Campbell Ave.

Dr. Butler literally "wrote the book" – *Forensic DNA Typing: Biology, Technology and Genetics of STR Markers* (2nd Edition). Elsevier Academic Press, New York (2005) and holds the patent on "DNA typing by mass spectrometry with polymorphic DNA repeat markers."

Dr. Butler Program Evaluation Results
Friday, March 9, 2007

Notes: 175 fliers were printed; 82 fliers were returned; 31 evaluations returned; estimated attendance 95 people. Some evaluations had 1 side (usually the front) left blank.

Did you enjoy tonight's presentation? 1 ….. 2 ….. 3 …3.. 4 ….. 5 …26..
(not at all) ……(very much)

Do you understand more about the field of genetics after this lecture?
1 ….. 2 …1.. 3 …3.. 4 …12.. 5 …11..
(no) ……..…... (a lot more)
(several people noted it was already their field of expertise)

Did the speaker seem knowledgeable about his subject?
1 ….. 2 ….. 3 ….. 4 …1.. 5 …28..
(no) ……..…(very knowledgeable)

Was the length of the talk appropriate?
1 …1.. 2 …1.. 3 …10.. 4 …8.. 5 …9..
(too short)……...(too long)

Did the speaker adequately respond to questions from the audience?
1 ….. 2 ….. 3 ….. 4 …7.. 5 …23..
(no)…….(yes, quite well)

How important do you believe it is for the general public to be educated about the field of genetics?
1 ….. 2 ….. 3 …5.. 4 …16.. 5 …12..
(not important)...……....(essential)

This presentation made me want to learn more about genetic research
1 ….. 2 ….. 3 …4.. 4 …12.. 5 …13..
(not at all)……..…(very interested)

Was this location easy for you to reach?
1 ….. 2 ….. 3 …2.. 4 …7.. 5 …22..
(no)…….....…(yes)
[1 comment received that Friday night was a bad time]

Please list any genetic-related topics about which you would like to learn more (i.e., genetic counseling, crime lab genetics, cancer treatment, etc.)
Cancer treatment (6)
Crime lab genetics (3)
Genetics related to human evolution (2)
Genetics & race
Beneficial or potentially beneficial mutations
Genetic counseling
Forensic jobs
Hereditary genetics
Aging
Alzheimer's research
Genetics of mental illness
How to get personal testing for medical purposes

How did you hear about this lecture? (list all that apply)
NPR/Radio 9
Friend/family member 8
Email 7
Mentor/professor 4
Genetics class 4
Advertisement
Colleague

How likely are you to attend a future lecture in this Genetics Education series?
1 ….. 2 ….. 3 …5.. 4 …11.. 5 …15..
(not at all) ……...(definitely)

Miscellaneous comments:
"Enjoyed it a lot!"
"I just really appreciate you offering these lectures!"

THE UNIVERSITY OF ARIZONA.
Graduate Interdisciplinary Program in GENETICS

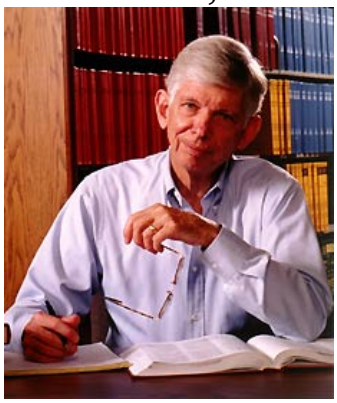
Sponsored by a grant from the Mountain States Genetics Network
Presents

"Why We Call Cancer A Genetic Disease"

by

Alfred G. Knudson, Jr., M.D., Ph.D.

Senior Advisor to the President, Fox Chase Cancer Center



A Free Public Education Seminar

Friday, April 20, 2007
7:00 pm
Duval Auditorium, University Medical Center
1501 N. Campbell Ave.

Dr. Knudson is internationally recognized for his "two-hit" theory of cancer causation, which explained the relationship between the hereditary and non-hereditary forms of a cancer and predicted the existence of tumor-suppressor genes that can suppress cancer cell growth. He received the 2004 Kyoto Prize, considered among the world's leading awards for lifetime achievement.

Program Evaluation Results – Alfred Knudson Public Education lecture 04/20/07:

Notes – A total of 10 evaluations were returned. We printed 120 programs/evaluations, and 100 were leftover. The head count I took during the lecture indicated that attendance was 23 people. We expected a much higher attendance, due to the popularity of the cancer topic, and utilized all of the same advertising avenues as previously. One explanation could be that the American Cancer Society was holding their "Relay for Life" on the same evening, and we suspect much of our target audience chose to attend that event.

Did you enjoy tonight's presentation?
1 ….. 2 ….. 3 ….. 4 ….. 5 …..
(not at all) ……(very much)
Average = 4.3

Do you understand more about the field of genetics after this lecture?
1 ….. 2 ….. 3 ….. 4 ….. 5 …..
(no) …….. (a lot more)
Average = 4.4

Did the speaker seem knowledgeable about his subject?
1 ….. 2 ….. 3 ….. 4 ….. 5 …..
(no) ……(very knowledgeable)
Average = 5.0

Was the length of the talk appropriate?
1 ….. 2 ….. 3 ….. 4 ….. 5 …..
(too short)…….(too long)
Average = 3.5

Did the speaker adequately respond to questions from the audience?
1 ….. 2 ….. 3 ….. 4 ….. 5 …..
(no)……(yes, quite well)
Average = 4.7

How important do you believe it is for the general public to be educated about the field of genetics?
1 ….. 2 ….. 3 ….. 4 ….. 5 …..
(not important)...……....(essential)
Average = 4.6

This presentation made me want to learn more about genetic research
1 ….. 2 ….. 3 ….. 4 ….. 5 …..
(not at all)……(very interested)
Average = 4.0

Was this location easy for you to reach?
1 ….. 2 ….. 3 ….. 4 ….. 5 …..
(no)……..…(yes)
Average = 4.6

How likely are you to attend a future lecture in this Genetics Education series?
1 ….. 2 ….. 3 ….. 4 ….. 5 …..
(not at all) ……...(definitely)
Average = 4.2

Please list any genetic-related topics about which you would like to learn more (i.e., genetic counseling, crime lab genetics, cancer treatment, etc.)
Genetic counseling (2); cancer treatment (5)

How did you hear about this lecture?
(list all that apply)
Radio (5); UA class/professor (2); Internet (1); Friend (1)

Total public attendance for 3 lectures = 168 people

30 names collected for Future Notice mailing (email or postal) list

Genetics Educational Forum – Presentation to Navajo IRB – July 17, 2007

Abstract: Geneticists at the University of Arizona wish to initiate a dialog about genetics with Native American Tribes. Our agenda is educational only – we aim to learn the concerns of Native Peoples and answer questions about the use and abuse of genetic information and studies. This proposed dialog is funded by a grant from the Mountain States Genetics Regional Collaborative Center through the National Institutes of Health to the University of Arizona Graduate Interdisciplinary Program in Genetics. **This is not a research project**.

The coordinator on the University of Arizona side is Murray Brilliant, Ph.D., Lindholm Professor of Genetics in the Department of Pediatrics. Our team includes clinical and research geneticists from the University of Arizona and colleagues from the IHS, National Institutes of Health, Translational Genomics Institute, and includes Native American Graduate students working on their Ph.D.s in Genetics.

We envision a true dialog and, as such, the agenda will be determined in collaboration with our Native American Hosts. For the purposes of initiating the discussion, we propose three agenda items: 1) a discussion of genetic principles illustrated by the genetics of corn and sheep; 2) a discussion of specific genetic disorders and their inheritance and prevalence among Native Peoples; and 3) a discussion of the uses and abuses of genetic studies involving Native Peoples. We are open to other agenda items and plan to modify the actual agenda in collaboration with our Native American hosts. In particular, we would like to partner with the Navajo Nation IRB, so that the forum will include the process of the IRB in the protection of the Navajo People.

If we can, we envision having the first of these dialogs sometime this summer in Tuba City, Arizona, so that we can involve the Navajo and Hopi Peoples. However, we are sensitive to cultural events and the needs of our hosts and will work together to find an appropriate time and place. There will be no costs to the participants. We have funds to bring our scientists and physicians to Tuba City, to advertise the event and pay for rental of a hall. We plan to locally cater a lunch that will be provided free to the participants. We will also arrange for an appropriate opening and closing ceremony for the event.

Although we are not proposing a study, Beverly Pigman and I thought it would be important to bring our proposed Educational Outreach and Forum on Genetics to the attention of the Navajo Nation IRB. It is hoped that with the help and participation of the Navajo Nation IRB, we can work together to discuss the important issues and concerns surrounding genetics.

I have tried to follow the format for Research Application Protocols, but because this is not a study, not all sections are applicable. I would be happy to provide any additional information and meet in person with the Navajo Nation IRB.

Community Involvement:

We hope to hold the Forum in Tuba City.

Community involvement is the reason to have the Genetics Education Forum. We envision a true dialog and intend to listen and understand the concerns that the Navajo people have about Genetics. We note that our group includes two Navajo graduate students working on their Ph.D.'s in Genetics. We want to have an active exchange. We want to partner with the Navajo Nation IRB so that together we can advance community knowledge about Genetics and the role of the Navajo Nation IRB in the protection of the people.

We invite wide community participation and intend to advertise the event on local radio and in the local newspaper. We will also involve local families touched by genetic disorders. We will invite community members to perform the opening and closing ceremonies catering the lunch.

We will report the outcome of the forum to the funding agencies (Mountain States Genetics Regional Collaborative Center and the National Institutes of Health). We will submit copies of all such reports to the Navajo Nation IRB. If we do publish a summary of the planning and evaluation of the forum, including the feedback (concerns expressed at the forum) that we receive, we will submit it first to the Navajo Nation IRB for approval.

Benefits to the Navajo Nation:

We understand that the Navajo Nation currently has a moratorium on Genetic testing. We respect the autonomy of the Navajo Nation to determine its own policy on Genetic testing. Our agenda is to understand the concerns of the Navajo people and share our expertise in genetics in the context of a two-way discussion about genetics. We believe that under certain circumstances, genetics can be of benefit to the Navajo Nation. One such example is in Newborn Screening for genetic disorders. As a matter of public health policy, newborns (including Navajos) are tested for enzyme deficiencies that, when treated early, prevent poor outcomes such as mental retardation and even death. Although they do not currently involve analysis of DNA, these are genetic tests that save lives. These tests now use a variety of chemical analyses to look for enzymes and their products. However, in the not-so-distant future, these tests will be DNA based. It is critical and life-saving to do Newborn screening whether or not DNA is used.

Research Project Description and Informed Consent: This is not a research project, but an educational program and so there are no informed consent forms. We aim to partner with the Navajo IRB to hold a public forum on genetics and the role of the Navajo Nation IRB in protecting the Navajo People. We envision a two-way dialog on genetics. We will cover what genetics is and what it isn't and we will listen to the concerns of the Navajo People about genetics issues. We believe that such a forum will also help the Navajo Nation IRB in efforts to publicize its role in protecting the Navajo people. We very much wish to coordinate our efforts with the Navajo Nation IRB for the benefit of the Navajo People. Our goal is to foster an understanding of genetics, including its uses and abuses. We aim to understand the concerns of the Navajo People regarding genetics.

The final organization of the forum will be coordinated with the Navajo Nation IRB. We suggest opening the forum with an appropriate ceremony performed by someone chosen in consultation with the IRB and local officials. This would be followed by introductions of the participants. The first part of the program would include presentations on the basic principals of genetics using corn and sheep. The second part of the program would switch to human genetics, genetic disorders (especially those found among Navajos), genetic tests and newborn screening tests. This will be followed by a question and answer period, with the specific aim of learning the concerns of the Navajo People regarding genetics. We will then break for lunch and more informal discussions. After lunch we envision a presentation about the role of the Navajo IRB in protecting the Navajo People. The final part of the program will be a discussion about the future of genetics, including its potential benefits and potential problems, especially with regards to the Navajo People. We will have a closing ceremony.

Our panel will include (depending on availability):

Murray Brilliant, Ph.D., Lindholm Professor of Mammalian Genetics, Chair Graduate Interdisciplinary Program in Genetics, University of Arizona College of Medicine

Robert Erickson, M.D., Holsclaw Professor of Genetics, Department of Pediatrics University of Arizona College of Medicine

Vicki Chandler, Ph.D., Carl E. and Patricia Weiler Chair for Excellence in Agriculture and Life Sciences, Regents' Professor, Dept. of Plant Sciences, Director of The BIO5 Institute University of Arizona

Michael Trujillo, M.D., MS, MPH Program Development and Outreach, Translational Research Institute and Former Director of the IHS.

Leslie Baier, Ph.D., Phoenix Epidemiology and Clinical Research Branch, Investigator, National Institute of Diabetes and Digestive and Kidney Diseases, National Institutes of Health

Nanibaa' Garison, Navajo Graduate student in Genetics, Stanford University

Robert Valenzuela, Navajo Graduate Student in Genetics, University of Arizona

We also hope to have **Trish Thomas** from Family Voices, **Jill Shuger**, M.S.
Genetic Services Branch, HRSA/Maternal and Child Health Bureau and representatives from the Mountains States Genetics Regional Cooperative.

Certification by the Principal Investigator. I have modified the form, as this is not a research project, but an educational project. I am fully aware of my responsibilities to the IRB in the event that the IRB approves this educational project.