

CPWR TECHNICAL REPORT

GENETIC TESTING FOR BERYLLIUM: WORKER KNOWLEDGE, BELIEFS AND ATTITUDES

February 2009

**Ken Silver, D.Sc.
and
Gary Kukulka, Ph.D.**

© 2009, CPWR – The Center for Construction Research and Training

Research for this report was funded by CPWR – The Center for Construction Research and Training, using grant U54 OH008307 from the National Institute of Occupational Safety and Health (NIOSH). The contents are solely the responsibility of the authors and do not necessarily represent the official views of NIOSH.

CPWR is a 501(c)(3) nonprofit research and training institution created by the Building and Construction Trades Department, AFL-CIO, and serves as the research arm of the BCTD. CPWR provides safety and health research and information for the construction trades and industry. For more information, visit www.cpwr.com.

ACKNOWLEDGEMENTS

We wish to express our utmost appreciation to Trish Quinn of the Center to Protect Workers' Rights, our grant manager. The suggestion to develop a written recruitment plan contributed greatly to the success of the project, resulting in twice as many participants as initially thought possible, and a richer collection of data.

The New Mexico focus groups would not have been possible without the leadership of Professor Hilario Romero (Northern New Mexico College), Paul Montoya of Española, Richard Espinosa (Sheet Metal Workers Local Union 49) and Dan Valerio of El Rio Arriba Environmental Health Association. Sound technician Debra Begel produced flawless recordings. Loyda Martinez, Bill Van Buskirk and Filimon Casados lent early support. Representatives of the Los Alamos Project on Worker Safety and the New Mexico Alliance of Nuclear Worker Advocates made the luncheon between focus groups in Española a spirited and informative occasion.

In Tennessee Bob DeBusk of the Construction Industry Outreach Foundation gave up his spring Saturday to provide a union hall for the Knoxville focus groups. We are indebted to Glenn Bell, Gary Foster, the Knoxville Building Trades Council, AFL-CIO and the Building Trades Medical Screening Program, as well as several business agents, for help with recruitment.

Dr. Kathleen Rayman of the ETSU College of Nursing and Dr. Richard Sharp of the Cleveland Clinic Foundation provided seminal ideas and critical input at key stages of the project.

In the Department of Family Medicine at ETSU, James Gorniewicz mastered NVivo7, coded transcripts, and provided reliable technical assistance. Patti Dugger and Susan Gardner ably transcribed the focus group tape recordings.

Staff travel and timely delivery of stipend checks to participants would not have been possible without Chuck Patton of the Department of Environmental Health at ETSU. Dr. Robert Pack provided thoughtful comments and E. Richard Brown had proofreading and editorial suggestions.

Part of a generous donation to the ETSU Research Foundation by Alex and Adeline Smith of Albuquerque was used to pay for lunches and tokens of appreciation for focus group participants. A larger share was used to organize the June 2008 beryllium forum in New Mexico where our interim findings were "reported back" to the community. Greg Winters (ETSU MPH candidate) arranged for Oak Ridge beryllium workers to teleconference with their peers in Española.

TABLE OF CONTENTS

	<u>page</u>
Abbreviations	iii
Executive Summary	1
Introduction	4
Methods	
Focus Group Guideline Questions	7
Recruitment	9
Analysis	11
Reporting to Stakeholders	11
Results	
Knowledge	11
Benefits and Burdens of Testing	14
Voluntariness	17
Sponsorship and Venue	18
Family Issues	20
Voluntary Self-Disclosure of Test Results	21
Risk Numbers	22
Medical Removal Protection Benefits	24
Insurability	27
Discussion and Conclusions	
Knowledge, Beliefs and Attitudes	28
Benefits and Burdens of Testing	29
Venue and Sponsorship	30
1. Primary Care	32
2. Chest Physicians	35
3. Former Worker Programs	35
Recommendations	38
References	39
Tables	43
Appendix A. Certificate of Confidentiality	
Appendix B. Hierarchy of Coding Concepts	
Appendix C. Agenda of Beryllium Forum (Española, NM) June 28, 2008	
Appendix D. Presentation at APHA (San Diego, CA) October 28, 2008	

ABBREVIATIONS USED

ADA	Americans with Disabilities Act
BeS	beryllium sensitivity (acquired)
CBD	chronic beryllium disease
DNA	deoxyribonucleic acid
DOE	U.S. Department of Energy
EEOC	U.S. Equal Employment Opportunity Commission
GINA	Genetic Information Nondiscrimination Act
Glu69	glutamine in place of lysine or arginine at position 69 in the HLA-DPB1 gene product; the marker first identified for genetic susceptibility to beryllium
GTM	grounded theory methodology
LANL	Los Alamos National Laboratory, Los Alamos, NM
LPT	lymphocyte proliferation test
MRPB	medical removal protection benefits
NIOSH	National Institute for Occupational Safety and Health
OEM	occupational and environmental medicine
ORNL	Oak Ridge National Laboratory, Oak Ridge, TN
PPV	positive predictive value
SNL	Sandia National Laboratory, Albuquerque, NM
Y-12	Y-12 National Security Complex, Oak Ridge, TN

EXECUTIVE SUMMARY

INTRODUCTION

Beryllium is the first industrial toxicant for which a scientifically valid genetic susceptibility test may soon be available. The gold standard for a screening test is the positive predictive value (PPV).^{*} For the Glu69 marker it ranges from about 12 to 43%. Certain rare alleles have been identified with PPV's ranging up to 100%.

Title II of the Genetic Information Nondiscrimination Act of 2008 (GINAct) prohibits employers' use of genetic information in employment decisions. The prohibition extends to unions and joint labor-management entities. None of these actors may "request, require or purchase" genetic information.

In this project we sought to gain insight into workers' knowledge, beliefs and attitudes on the subject of genetic susceptibility testing for beryllium.

METHODS

Five focus groups were held with 30 current and former workers and nine of their family members between June 2007 and April 2008 in New Mexico and Tennessee. Workers were employed at the following Department of Energy (DOE) facilities: Los Alamos National Laboratory (LANL), Sandia National Laboratory (SNL), Oak Ridge National Laboratory (ORNL) and the Y-12 National Security Complex.

The facilitator used the following guiding questions:

1. Should workplace testing be offered to all workers or just some workers? Should it be optional or mandatory?
2. How would individuals benefit from taking a genetic susceptibility test? What burdens would they face as a result of taking the test?
3. What factors would increase or decrease your likelihood of pursuing testing?
4. How would you respond to a positive test result? To a negative test result?

RESULTS

Knowledge and Beliefs. LANL participants' knowledge was rooted in personal experience with health outcomes and exposure scenarios. Questions raised by participants were the layperson's version of those being pursued by scientific researchers. Differences in knowledge and beliefs between LANL and ORNL/Y-12, where a beryllium support group meets regularly, could be helpful in developing worker education programs on genetic testing. Some misconceptions involved the distinction between genotoxicity and heritability, as well as the role of smoking in chronic beryllium disease (CBD).

Benefits. Overwhelmingly, the perceived benefits of a positive test result were related to the principle of individual autonomy. Participants also said they would use the

^{*} PPV is defined as the proportion of people who will develop the disease among those who test positive.

knowledge of their own susceptibility to steer their children away from careers with beryllium exposure.

Burdens. The major burden cited by participants was the potential abuse of genetic information by employers. As GINA takes effect, perennial aspects of the work and social environments in nuclear communities will surely persist, such as the inadequacy of sanctions under health and safety laws and contractor non-compliance. Not even a hypothetical voluntary program with up-front promises of confidentiality was sufficient to fully allay workers' privacy concerns.

Voluntariness. The vast majority of responses were in favor of voluntary testing. Concern for "civil liberties" was cited in opposition to mandatory testing.

Sponsorship and Venue. Overwhelmingly, participants' comments focused on ensuring financial and political independence of the testing entity from the employer. Involvement of representatives of outside groups was suggested. At Oak Ridge it was suggested that a worker's private physician could administer the test and help the worker's family interpret the result.

Family Issues. A heritable susceptibility marker would have implications for a worker's family. Family members figured prominently as key figures to whom workers would disclose their test result. Family contact exposure via contaminated work clothes was widely recognized as hazardous. Dissatisfaction was expressed over the lack of free LPT testing for family members through DOE's former worker programs

Voluntary Self-Disclosure. Divergent views were expressed on disclosing a test result to the employer.

Risk Numbers. Does a positive genetic test tell you something you don't already know? We premised this question on a 5% current known risk of disease; after a positive genetic test, it goes up to 14%. Only one participant, a union official, fully accepted the premises of the question and provided an unambiguous answer: "That's so important." Numerical estimates of risk from the various lines of scientific evidence may need to be processed in a group setting.

MPRB. Some of the most vexatious issues of a voluntary genetic susceptibility program for beryllium have already been encountered under DOE's beryllium standard which provides "medical removal protection benefits" for workers who are LPT-positive. Even so, some younger workers at Oak Ridge/Y-12 are eschewing the LPT to avoid potential stigmatization and prolonged joblessness.

Insurability. Threats to individuals' insurability were the subject of much comment and strongly held opinions. Beryllium workers are vulnerable when they change employers and when they apply for supplemental insurance in retirement.

DISCUSSION AND CONCLUSIONS

Those concerned with the responsible use of a genetic test for susceptibility to beryllium may now be enjoying a calm interlude. Commercialization could interfere with the phased approach to translational research which consists of needs assessment, intervention and longitudinal follow-up of outcomes.

We evaluate three possible venues for a voluntary, confidential genetic testing program:

1) **Primary care physicians.** Workers in our focus groups trusted their family doctor. But a strategy centered on primary care practitioners may be overly ambitious.

2) **Chest physicians.** Pulmonary specialists near DOE facilities already have relevant expertise. But as specialists they are more likely than family physicians to have financial ties to the employer's medical program.

3) **Former worker programs funded extramurally by DOE.** Many of these teams include occupational physicians and staff who are committed to protecting the rights of DOE employees. They are well-situated to keep abreast of the science on genetic markers as well as strategies for tailoring genetic counseling protocols to the work environment. The files of participants in medical surveillance projects are smaller than patient records in a private medical practice. Extensive privacy protections are in place. So a genetic test result is less likely to be inadvertently transmitted to anyone other than the worker.

In a phased approach, the genetic susceptibility test could be made available first to *former* workers. These pilot programs could serve as the proving ground for educational programs and materials, as well as counseling. Former workers could be cultivated as leaders in later efforts to consider offering genetic testing on a voluntary, confidential basis to *current* and *prospective* workers.

With research in molecular epidemiology and modeling ongoing, the test's PPV may increase in value. Should the PPV exceed 50%, there won't be many winning arguments standing in the way of commercial availability of a genetic test. A positive result would mean "more likely than not" the person will develop disease. Those concerned with protecting workers' rights currently have a window of opportunity to control genetic testing to ensure that, if it is used, then it will be used to the benefit, not the detriment, of workers and their families.

RECOMMENDATIONS

Eleven recommendations for individuals and organizations concerned with workers' rights are made on page 38.

INTRODUCTION

Genetic analysis in epidemiologic studies of worker populations has revived the prospect of genetic testing for susceptibility to illnesses caused by workplace toxicants, long a topic of lively debate in occupational health policy. [1, 2] Early controversies brought to the fore concern over employer mandates, along with issues of worker privacy and other rights.[3] Much debated was the potential for genetic testing to shift attention to removal of “susceptibles” and away from traditional industrial hygiene controls intended to make the workplace safe for all. [4, 5] Interestingly, this debate unfolded decades before any genetic tests were available which actually met scientific standards for use in screening.[6] Despite the long period of anticipation, today it remains unclear as to whether adequate policies will be established in time to prevent the potentially disruptive social effects of genetic testing.[7-9]

Beryllium is the first industrial toxicant for which a scientifically valid genetic susceptibility test may soon be available.[10] Initially, a glutamic acid substitution for lysine or arginine in position 69 of the HLA-DPB1-0201 allele of the major histocompatibility complex (“Glu69”) was found to be associated with elevated risk of chronic beryllium disease (CBD).[11] This marker has moderate to high sensitivity; it is present in 72 to 92% of workers with CBD. But it has low to moderate specificity: the marker is present in 30 to 45% of exposed workers who are unaffected by beryllium sensitivity (BeS) or CBD.

The gold standard for a screening test is the positive predictive value (PPV), defined as the proportion who will develop the disease among all who test positive.[12] For the Glu69 marker it ranges from about 12 to 43% under reasonable sets of assumptions for disease prevalence, relative risk and allelic frequency.[13] However,

more recently certain rare alleles have been identified with PPV's ranging up to 100%.^[14] These PPV's are, in fact, estimates derived from a compelling mechanistic model which integrates molecular epidemiologic findings with the biophysical chemistry of beryllium's binding to variant protein products of the HLA-DPB1 gene.^[15] While these estimates could change with refinements to the model, the presence of an allele with a PPV of 100% in a beryllium exposed worker would predict to a high degree of certainty that the worker will develop CBD.

Previous social science research with beryllium workers includes a formal assessment of a worker notification program aimed at increasing self-protective behaviors in the workplace and reducing the potential for family contact with beryllium dust on work clothes and in family automobiles.^[16] There have been a few halting efforts to explore workers' knowledge, beliefs and attitudes toward genetic testing. Among beryllium workers enrolled in NIOSH studies of genetic markers, a small percentage (6.2%) requested their individual results.^[17] Workers enrolled in a genetic study at Los Alamos National Laboratory in the late 1990's may have been provided with information about their susceptibility status, along with genetic counseling.^[18, 19] A labor-based program which assessed the attitudes of workers, some of whom had had the genetic test along with the more widely used non-genetic lymphocyte proliferation test (LPT), emphasized the importance of administering such tests in surroundings and under conditions of the workers' own design. Issues of access to records, reliable information sources, certainty in payments for follow-up care and holistic involvement by unions were identified.^[20]

As early as 1992 Holtzman foresaw that genetic tests with low acceptance, low PPVs and high potential for insurance discrimination would be applied in the "default destination" of family-centered testing, not in population screening. Arguably, the

Glu69 marker meets at least two of these conditions. Hence, family medicine and other primary care practitioners are candidates for administering the test to workers on a voluntary basis. Currently, primary care providers are ill-equipped to evaluate genetic tests for a rare occupational disease like CBD. However, given past efforts to infuse occupational medicine into primary care practice, they may be highly educable, especially on the ethical and social implications of genetic testing.[21]

In April 2008 the United States Congress passed, and the president later signed, the Genetic Information Nondiscrimination Act (GINA, Public Law 110-233), breaking a Congressional stalemate of 13 years. Title II prohibits employers' use of genetic information in employment decisions. The prohibition extends to unions and joint labor-management entities. None of these actors may "request, require or purchase" genetic information.[22] Individuals who believe they have experienced disparate treatment at work on the basis of genetic information may seek compensatory and punitive damages at tort up to a cap of \$300,000, but only after exhausting administrative remedies under state law and with the federal Equal Employment Opportunity Commission (EEOC).[23] Implementing regulations are due out in 2009.[24]

Critics have noted that while Title I of GINA prohibits the use of genetic information in health insurance, it does not cover disability, long-term care or life insurance.[7] Moreover, the Americans with Disabilities Act (ADA) demonstrates how the high-minded intentions of a federal statute can be eroded during the implementation phase by narrow judicial interpretations.[25, 26] Repetitive strain injury in a factory worker was ruled by the U.S. Supreme Court to fall outside the meaning of a "disability" because only work-related activities were impaired, not other major activities of daily life.[27, 28] Also, in a case with potential implications for susceptibility research, the Supreme Court held that a petrochemical refinery could exclude a worker with hepatitis

C on the grounds that his liver might have heightened susceptibility to chemical toxicity. The range of choices available to workers who are aware they have a susceptibility trait but autonomously prefer to assume the risk was narrowed.[29] While GINA offers a new legal framework, some interplay with ADA case law seems plausible.

News of GINA's passage came one week before the final focus group event (Knoxville, TN) of the project described in this report. A news article about GINA was distributed along with miscellaneous fact sheets about beryllium at the lunch which was provided for focus group participants. But the law's implications were not raised by the participants in the focus groups.

In this pilot project we sought to gain insight into workers' knowledge, beliefs and attitudes on the subject of genetic susceptibility testing for beryllium. We aimed to clarify the consequences of genetic testing and how it is understood and considered by employees at DOE facilities and family members. From these findings, we intend to clarify policy alternatives on genetic susceptibility testing for beryllium for organizations representing workers.

METHODS

Focus Group Guiding Questions. The interdisciplinary project team included an environmental health scientist (principal investigator), a qualitative researcher (facilitator), a bioethicist and a nurse researcher who consulted on the qualitative process. This team developed questions to guide the discussion of each focus group:

1. Should workplace testing be offered to all workers or just some workers?
Should it be optional or mandatory?

2. How would individuals benefit from taking a genetic susceptibility test? What burdens would they face as a result of taking the test?
3. What factors would increase or decrease your likelihood of pursuing testing?
4. How would you respond to a positive test result? To a negative test result?

The facilitator adhered to these questions, but also probed spontaneously on provocative or ambiguous points as they arose. The facilitator used the device of asking the three worker focus groups to consider themselves “the committee” charged with establishing a policy for the genetic test for their peers on the job. In the course of responding to the guiding questions presented in this context, participants raised questions of their own and revealed varying levels of knowledge about genetic testing, along with their beliefs and attitudes.

Of particular interest was how workers think about probabilistic issues associated with use of a predictive genetic susceptibility test. The focus groups were asked to assume a 5% prevalence of disease. Then participants’ attitudes toward a genetic susceptibility test with a PPV of 14% were elicited to shed light on how workers would value the new information provided by such a test.

Each focus group began at 9:30 AM with acknowledgements of and welcoming remarks by leaders of the facilities hosting the sessions (a community college and two union halls). Paper work for stipend payments was completed over coffee and refreshments. The principal investigator conducted the informed consent process, answered questions, and attempted to elicit critical questions or concerns from any union stewards present. Participants completed a brief demographic questionnaire (Table 2) with a tear sheet linking their number to their identity; these tear sheets constitute the only key to individual identities. By the time of the April 2008 focus

groups in Knoxville, TN, a certificate of confidentiality had been obtained from the Centers for Disease Control and Prevention, to rigorously protect individual identities from disclosure (Appendix A).[30, 31]

The facilitator established several rules: 1) respect for the confidentiality of participants' remarks ("What is said here stays here"); 2) there are no right or wrong answers; 3) only one person speaks at a time; 4) respect for each other's contributions. In addition, a comment card was provided in a postage paid envelope for participants to transmit afterthoughts to the research team.

The facilitator sat at eye level with the participants at conference tables with circular or horseshoe arrangements. Participants were assured that the tape recordings would be destroyed after the final transcripts were generated. The principal investigator left the room. He was able to observe two of the focus groups in their entirety from a separate location, and partially observe two focus groups while sitting apart from the conference table. Before launching into the first guiding question the facilitator elicited a round of self-introductions. In the facilitator's own background were family roots in the coal mining regions of Appalachia and a stint as a union auto worker.

Recruitment. The approaches used in New Mexico and Tennessee to recruit focus group participants were based on the principal investigator's history and familiarity with key contacts among beryllium exposed workers and organizations that represent their interests. At Los Alamos and Sandia National Laboratories in New Mexico (LANL and SNL, respectively), approximately half of the participants were recruited through union stewards and business agents. The remaining participants were identified through a community-based advocacy organization with a history of involvement in

nuclear worker issues. This avenue was seen as critical because many beryllium-exposed workers at Los Alamos have never had union representation as employees of the University of California, the federal contractor operating LANL.

At Oak Ridge (Oak Ridge National Laboratory [ORNL] and the Y-12 National Security Complex), key contacts furnished by the Center to Protect Workers' Rights in the regional labor council of the American Federation of Labor – Congress of Industrial Organizations (AFL-CIO) yielded the majority of participants. Additionally, focus group participants were recruited through informal contacts made by members of a beryllium support group which meets regularly in Oak Ridge, as well as through a community-based organization that has long advocated on nuclear worker issues.

We aimed to hold separate focus groups with first degree family members of beryllium-exposed workers, in keeping with social science research on other genetic susceptibility traits.[32, 33] Project recruitment materials simply asked beryllium workers to invite their spouse or other family member to participate in the afternoon focus groups. Spouses were always placed in separate focus groups.

To provide an inducement and offset personal expenses for time and travel, all participants were paid a stipend of \$150, which was budgeted for in the grant proposal. Most participants gave up a half day (four to six hours) on a weekend. In addition, a free lunch was provided to all participants along with tokens of appreciation (e.g., ETSU coffee mugs). These items were paid for out of non-grant funds.

The distribution of the focus group participants (N=39; 30 workers and 9 family members) by locale and session is in Table 1. Nearly half were Hispanic or African-American.

Analysis. Tape recordings of the focus groups were transcribed and entered into the software program NVivo 7. All transcripts were coded by hand by the principal investigator (environmental health scientist), then the coding was revised as it was entered into NVivo 7. A psychology graduate student independently coded the three New Mexico transcripts directly in NVivo7. The complete hierarchy of conceptual labels developed in the process of coding the transcripts is in Appendix B. Verbatim statements of focus group participants for each concept in the hierarchy were printed and bound into 3-ring binders. This facilitated the analysis of responses to the guiding questions and the selection of exemplar remarks quoted in this report.

Reporting to Stakeholders. On June 28, 2008 a community forum on beryllium was held in Española, NM at Northern New Mexico College where the focus groups had been held a year earlier (Appendix C). Only non-grant funds were used for this meeting. Part of the agenda was a “report back” by the facilitator on our interim findings of this study. Several of the focus group participants were present. They provided feedback on the direction the analysis had taken.

RESULTS

Knowledge

Consistent with grounded theory methodology (GTM), the research team did not disseminate educational literature or present information about genetic testing in advance of the focus groups. A principal aim of the study was to ascertain participants’ knowledge, beliefs and attitudes as they existed when invitations to participate were issued.

A striking, systematic difference between LANL and ORNL/Y-12 in the resources locally available for workers to become knowledgeable about beryllium presents an important opportunity which could guide the development of worker education programs on genetic testing. A beryllium support group meets regularly at Oak Ridge. In the Knoxville, TN focus groups it was clear that workers engaged in the support group had gained sophisticated insights and information about beryllium sensitivity and genetic testing, which they have disseminated to their peers. For example, an active participant in the support group explained:

“You can be exposed just one little bitty time and then be super susceptible to it. They show symptoms within three months. And then other people ... I’ve been around it for 27 years. And I might not show it for another 15 or 20 years, if I ever do. So that’s one thing about genetics. If they get it right, they can tell who would be super susceptible to it.”

The role of host factors in chronic diseases in general was colorfully illustrated by an Oak Ridge worker:

“I smoked for 40 years. And I eat deep fat fried foods. And I drink beer. But I’ve got good cholesterol. My bad cholesterol is low and my good cholesterol is high. And I’m in good health. Maybe I’ve just got the right genes.”

At LANL, where there is no support group, participants’ knowledge was rooted in personal experiences with health outcomes and exposure scenarios. Many of the participants were bilingual, with Spanish their lingua franca for discussing job-related issues among themselves. However, the focus groups were conducted in English. The LANL focus groups’ level of knowledge appeared to be comparable to that of healthy, active workers who are beryllium-exposed but have not yet been called upon to make presentations to their peers on the subject, as some of the Oak Ridge support group members had done, nor studied extensively the fact sheets provided at medical screenings. Few if any educational resources on beryllium are available in Spanish.

Interestingly, in the Española, NM focus groups the principal investigator was peppered with substantive questions about genetic testing. Consistent with grounded theory methodology, he declined to answer these questions until after the focus groups. Clearly, there was a desire for more knowledge among these LANL workers and family members.

Some questions raised in the LANL focus groups are essentially the layperson's version of those being pursued by scientific researchers: "If there is a group of people working together with beryllium only maybe four are sensitized to it ... So is there an explanation for that?" Similarly, "When they check you for sensitivity, what's the difference between that and genetics?" In the workers' own vernacular, these questions address the same fundamental questions that lie at the core of molecular epidemiologic studies underway at research institutes and universities. This spark of interest in biomarkers and issues of interindividual variability could form the basis for community- and labor-based partnerships on genetic testing issues.

By focusing on some of the misconceptions of participants, one can begin to appreciate the educational challenges which would confront a future program to make the genetic test available on a voluntary basis to active workers. The methods by which the genetic test is performed were not immediately obvious: "We don't have no idea of what a genetic test is. We don't know if they take blood, or your blood pressure. Or if they take a shot in your eye. Your urine? We have no idea." Another critical area is the distinction between heritability and genotoxicity. Several participants expressed the mistaken belief that a "genetic test" measures genotoxicity to subsequent generations: "I'm thinking of a child that hasn't been born yet." And: "If it alters your genetic material, that would alter your future generations." However, at least one other LANL participant did not share this misconception. He clearly understood that a genetic test

is aimed at measuring a heritable marker of susceptibility: “My children have the same genes as I do. So they’re probably going to be sensitive to it if I was.”

To illustrate their understanding of human variability in an immune (“allergic”) response, LANL participants drew analogies to peanut butter and alfalfa crops. Tuberculosis and asbestos were cited as lung diseases for which screening programs have long been available. There was a high degree of clarity about routes of exposure, including the importance of dermal exposure. Some misconceptions involved smoking as a positive co-factor for the development of CBD and “the percentage of people that are susceptible is ... less than 10%, if I remember correctly.” In fact, smoking may have a weak protective effect.[34] The percentage of the population that carries the Glu69 marker of susceptibility is 33% among Caucasians and 47% in Hispanics.[13]

Benefits and Burdens of Testing

Benefits. Two distinctions are critical to evaluating workers’ beliefs and attitudes toward the benefits of genetic testing. One distinction is between negative and positive test results. Another is between the views of current and former workers.

A negative test result would “ease the mind” and give individuals the “satisfaction of knowing” they lack the susceptibility marker, according to current LANL workers. But, overwhelmingly, the perceived benefits of a positive test result were related to the principle of autonomy. Various expressions of the possibilities for autonomous decision-making are summarized in Table 3. Similarly, former workers who are beryllium sensitized expressed remorse that a genetic susceptibility test was not available to them to make an informed decision when they began their careers. These participants said they would use the knowledge of their own susceptibility to steer their children away from careers with beryllium exposures.

Burdens. As expected, the major burdens cited by participants concerned the potential abuse of genetic information by employers. Passage of the Genetic Information Nondiscrimination Act (GINA), which prohibits employers from collecting or using genetic information, did not occur until the data-gathering phase of this project was nearly complete in April 2008. As GINA takes effect, perennial aspects of the work and social environments in nuclear communities will surely persist, such as the inadequacy of sanctions under most health and safety laws and contractor non-compliance:

“They do something beyond the law. So what? ‘We get caught. We get a \$5,000 fine. We get smacked. We promise not to do it again.’ But hell they’re going to do it again anyway.”

Workers will be skeptical about their employers’ likelihood of complying with GINA regulations (due out in 2009). Inseparable from the perceived threat of adverse actions by employers are threats to the privacy of genetic information. Not even a hypothetical voluntary program with up-front promises of confidentiality was sufficient to fully allay workers’ privacy concerns.

Workers’ attitudes about abuse of genetic information were directed both at employers in the private sector and at contractors at government-owned nuclear facilities. (See Table 4). The overwhelming majority of comments concerned the potential for adverse job removal actions. Yet one retired construction worker had a more sanguine view of the employer’s willingness and ability to provide alternative employment for workers who seek to be removed from beryllium jobs on the basis of a genetic susceptibility test: “You’ve gotta understand Los Alamos. They’ve got jobs all over the place. So if you can’t fit into beryllium, they’ve always got a job for you.” A measure of credence can be imputed to this statement by virtue of the fact that none of the focus groups revealed instances of frank discrimination against LPT-positive

individuals, notwithstanding other serious problems with the medical removal protection program under DOE's beryllium standard. (See MRPB below).

The focus groups at both LANL and ORNL/Y-12 described a special program whereby employees in jobs considered of "high risk" to national security consent to give their employer far-reaching access to their personal information, including medical and prescription drug records as well as banking and financial data. This is DOE's "Human Reliability Program."^[35] In the course of periodic, exhaustive assessments of the employee's medical, job task, psychological, and safety issues, enrollees feel obligated to report many private details of their lives to their employer. At Oak Ridge, those who volunteer for this program are paid an extra two dollars per hour over co-workers who demur. No such wage differential was explicitly mentioned at Los Alamos. At both sites it was felt that some enrollees would feel compelled to construe a genetic test result – even one obtained voluntarily with assurances of confidentiality – to be subject to the self-reporting ethos of the program. Thus, the employer's ability to learn of a worker's susceptibility status had an aura of inevitability: "It doesn't really matter who does the testing as long as you work for the government because they're going to find out," an enrollee said. "That's right," a co-worker agreed. "They're going to do whatever they want."

Several additional burdens of genetic susceptibility testing were articulated. Often cited was the psychological stress likely to be experienced by family members of workers who continue to work around beryllium after receiving a positive test result. "[T]hey would be worried day in and day out," one worker said of his family. (See Family Issues, below).

Exploitation of biological materials was also cited as a burden of participating in a testing program. Interestingly, this concern was expressed strongly in a focus group in Española, New Mexico, perhaps owing to the decades-long influence of organizations concerned with protecting the collective genetic resources of indigenous communities. [36, 37] One worker premised his comment about unauthorized use of DNA on the advent of a voluntary testing program at some point in the future. But another worker commented on his actual experience with the informed consent process carried out by a university's researchers during periodic medical surveillance exams: "They take blood – like four, five, six vials of blood. And you never know what they did with it or anything."

Possible burdensome effects of genetic susceptibility testing on co-workers were also cited. A union official asserted: "You can have 'Superman Syndrome'," whereby a worker who is negative for the genetic marker becomes careless in observing measures to reduce exposure to beryllium, endangering co-workers. Inversely, voluntary self-removal from jobs with beryllium exposure, based on a positive test result, raised a two-fold problem. First, "Everybody knows ... because he's not working with beryllium. So how do you really protect that person's privacy?" Second, drawing upon prior experience with light duty restrictions for physical injuries, a union officer predicted: "Well a lot of the other co-workers will give him s—t." That is, current policies for temporarily accommodating workers with physical injuries are met with resistance by construction workers. "Machismo" attitudes were cited.

Voluntariness

Our focus groups took place before passage of the GINA Act. One of the guiding questions (see pp. 7- 8) elicited workers' views on whether genetic testing should be

voluntary or mandatory. The vast majority of responses were in favor of voluntary testing. Concern for “civil liberties” was cited in opposition to mandatory testing. A union steward would predicate any offering of the test on participation in a mandatory educational program. “After education you have a choice” to take or refuse the test. A union construction worker suggested that employers pay release time to facilitate worker participation in a voluntary testing program. However, at Oak Ridge release time was viewed with suspicion, based on recent experience with a research study: “[Management] agreed to pay us off the clock. That way they know who was going up there to have this test done by [the research group].” Importantly, participants distinguished between management knowing who had participated in the study (i.e., yes/no) from the threat of unauthorized disclosure of their test results to management. The latter was not emphasized because of this research group’s careful data handling procedures.

Among the few expressing support for mandatory testing were workers who suggested limiting such a requirement to those with known exposure to airborne beryllium.

Sponsorship and Venue

A previous labor-oriented study concluded that genetic susceptibility and LPT testing should take place in surroundings and under conditions of the workers’ own design.[20] Our facilitator followed up the guiding question “What factors would increase or decrease your likelihood of pursuing testing?,” by probing for specifics about *who* should sponsor a voluntary testing program and *where* testing should take place. Participants were asked to think of themselves as “the committee” establishing policies for a testing program for their work peers.

Overwhelmingly, participants' comments focused on ensuring financial and political independence of the testing entity from the employer (Table 4). Under the hypothetical scenario of sponsorship by the employer, a worker asked "Are they telling you the truth when they say it's negative?". Specific suggestions were made for who should lead an outside testing entity that is independent of the employer. Involvement of representatives of the Centers for Disease Control, watchdog groups, and "an environmentalist ... someone who can't be bought" were suggested. A hybrid structure which would involve both labor and management was suggested by a retired construction worker:

"The companies oughta set up a safety board. And put the workers in charge ... Choose a guy that's a B.A. [union business agent]. And have him in charge. That way the workers can say what they feel and get the information they need."

Avoiding a sole source contracting arrangement by involving more than one testing facility was also proposed. This would reduce the risk of one testing lab, which becomes overly dependent upon the government or DOE contractor for funding, bending to the will of management in making clandestine disclosures of individuals' test results.

At Oak Ridge it was suggested that a worker's private physician could draw blood, receive the test results, and help the worker's family interpret them. "I trust my doctor to be honest. I don't trust them [the employer] to be honest at all." Similar sentiments were voiced in New Mexico, but with two caveats. First, the Los Alamos medical community, where some of the workers' personal physicians practice, is seen as being "intertwined" with the employer. Second, in light of past errors in interpreting other clinical test results, personal physicians were not viewed as being equipped to handle all aspects of a beryllium genetic test. Responsibility for an educational program might need to rest with some other entity.

Issues of distrust of employer involvement were voiced more consistently and earlier in the Tennessee worker focus group than in Española, NM. However, as the latter focus group's discussion proceeded many of the same concerns were articulated. We surmise that discussions at the Oak Ridge/Y-12 support group had solidified workers' views before our focus group was held. Lacking a beryllium support group, the New Mexico participants may have simply needed a prefatory discussion before arriving at views on issues of trust for the employer that are quite similar to those expressed at ORNL/Y-12.

Family Issues

Separate focus groups were held for family members of beryllium workers. (See Table 1). Family contact exposure via contaminated work clothes was widely recognized as a hazard. At Oak Ridge, dissatisfaction was expressed over the lack of free LPT testing for family members through DOE's former worker programs.

It was widely recognized that a heritable susceptibility marker would have implications for a worker's family. As noted earlier, some retired workers who are LPT positive would use knowledge of their own genetic susceptibility status to steer a child away from careers associated with beryllium. Some workers implied they would assume their own susceptibility status applies to their children, while others explicitly stated they would like to see their work age children get tested. Family members figured prominently as key figures to whom workers would disclose their test results. But some would refrain from doing so to avoid worried reactions about their safety as a breadwinner. (See page 16). At Oak Ridge a key distinction was drawn:

“Having the disease and telling your family is different than having a genetic marker and telling your family. Now I wouldn't tell my family that I had a genetic marker. I would hold that to myself, I think.”

One worker would disclose his genetic test result to his daughter for quite a different reason: “She’s studying to be an environmentalist” and therefore could assist him in critically evaluating the implications of his test result.

A favorable view of the prospect of a genetic susceptibility test was expressed by a current employee whose father, spouse and sibling are, respectively, dead from CBD, currently exposed, and LPT-positive: “Considering the history I have in my family, this would be just a perfect fit for my family.” A retired union steward viewed the prospect of a voluntary genetic testing program in the wider context of the role of unions in families and communities: “You’ve got to plan your future and your needs, your relatives, the people you’re around. And you’ve got to take care of your membership.”

Voluntary Self-Disclosure of Test Results

Probing beyond the guiding question “How would you respond to a positive [or negative] test result?,” the facilitator elicited from workers the key people in their lives to whom they would voluntarily disclose their test result. As noted earlier, most workers would disclose to family members. Disclosure to one’s personal physician, while favored by many participants, was complicated by the modern reality that workers in health plans or those suffering from chronic illnesses may have “two or three doctors. Which one gets it?”

In New Mexico, a greater proportion of workers would disclose a positive test result to their employer than would workers at Oak Ridge. One union construction worker, savvy about the internal decision-making structure of his employer’s organization, would tell “Somebody higher up than my immediate supervisor that I’m not gonna be working around that [beryllium] no more -- and hope they’d leave it at

that.” Another union worker would disclose his positive test result to “My fellow worker. ‘Hey my test came out positive, dude. So you’ve probably got it’” – by way of encouraging his co-worker to avail himself of a voluntary testing program. However, another participant expected a more guarded response:

“The employment in Northern New Mexico is mostly based on the Laboratory. A lot of people would not want to lose their employment – not tell – on the basis of being discriminated against.”

Divergent positions are expected in a voluntary program. Free choice leads to a diversity of outcomes. The sponsors of a voluntary program could disseminate guidelines which lay out the implications of self-disclosing test results to various actors, perhaps recommending non-disclosure. The range of responses described here may be helpful in developing guidelines.

Also revealing is that when asked on the demographic questionnaire about their individual BeS and CBD status, nearly half of the participants provided no response (18/37 or 48.6%; Table 2).

Risk Numbers

We wanted to learn whether workers would value the added information provided by a genetic susceptibility test. The PPV of the Glu69 marker is about 14% under assumptions that are realistic for today’s workplace (i.e., 5% prevalence of disease, equal numbers of Hispanics and Caucasians).[10] Construction workers in the DOE complex have about a 5% prevalence of beryllium sensitivity.[38] For the sake of simplicity, we asked focus group participants to assume that in the absence of a genetic test they “know” their risk of disease is about 5%. Does a positive genetic test which revises the risk number to 14% provide valuable information? Does it tell you something you don’t already know?

Only one participant accepted the premise of the question and provided an unambiguous answer: “If right now 5% of the people could be susceptible [sic] to it and they did the genetic studies and found out that it’s a lot more, it goes up to 15%, double or triple ... That’s so important.” Interestingly, this union official went on to refocus on environmental controls: “And what’s even more important is how the control levels change after they find out the increase.” This is the crux of the long-running debate in occupational health over the use of genetic susceptibility testing. The union official takes the position which has traditionally been the stance of organized labor, in opposition to those who would emphasize removal of workers rather than environmental controls. In this formulation the results of a genetic test *strengthen* the case for industrial hygiene controls.†

Several other participants rejected the question’s premise of a 5% risk of disease. Based on their life experience, and on-the-job discussions with co-workers, some placed the current known risk at the level of 25 to 50%. Another participant seemed to reject the underlying assumption that risks should be discussed in quantitative terms: “One percent is too much. If you are in the 1% group, adios.”

Another participant misconstrued the fundamental difference between prevalence and PPV, despite the facilitator’s steering clear of the use of these technical terms:

“It might also mean that the previous research wasn’t as thorough as it should have been. If the percentage is going up the old research may not be as significant as what the current research is showing.”

† The issue of cost minimization as a motive for genetic testing in place of engineering controls was raised by another focus group participant who accurately cited a 1994 article in which an industry executive favors screening out “susceptible” workers so as to eliminate the industry’s “marketing problem” of “expensive control measures.” [39]

This comment, however lacking in formal definitions, is helpful in thinking about the future development of popular education programs about genetic testing. This worker views older research as less “thorough” or “less significant,” whereas a scientist might say the genetic studies are “more refined” by virtue of using “cutting edge” molecular methods. As a practical matter, distinguishing too finely between prevalence and PPV may be a distinction without a difference.‡ Numerical estimates of risk resulting from the various lines of evidence may need to be processed in a group setting, not unlike our focus groups, for workers to sift through the data and draw conclusions that are meaningful and actionable in their lives.

Medical Removal Protection Benefits

Some of the most vexatious issues of a voluntary genetic susceptibility program for beryllium have already been encountered under DOE’s beryllium standard which provides for “medical removal protection benefits” (MRPB) for workers who are LPT-positive. Under the standard, employers are supposed to reassign sensitized employees to jobs with beryllium exposures “as low as possible but in no event at or above the action level” of 0.2 micrograms per cubic meter of air. Total earnings, seniority and other job rights and benefits must be maintained for two years.[40]

Implications of the LPT test inside the worksite as well as implications beyond the DOE contractor’s worksite were discussed.

‡ The case for loose adherence to formal definitions was demonstrated when a union representative at the American Public Health Association panel on October 28 (see Appendix D) asked “What about false positives?” To an epidemiologist, “false positives” are represented by the numerical expression for specificity. However, from the perspective of a union representative who may be advising members on whether to participate in a voluntary testing program, the notion of a false positive may be more closely akin to $1 - \text{PPV}$. With a PPV of 14%, the Glu69 marker will be incorrectly positive 86% of the time.

Inside the DOE Contractor's Worksite. Different kinds of failures were reported at Oak Ridge and in New Mexico. At Oak Ridge frank non-compliance with the MRPB provisions was alleged:

"I was a union steward and represented the individual, who's retired now, to try to get them out of exposed areas. For five years they [management] just nearly put an X on the wall, beating your head against it to try to get them away from exposed areas."

This problem affected several individuals. Another participant stated:

"There are several of us here that had to retire because they were still exposing us to beryllium, and still even up to my day of retirement. Even though the company already knew it ... But they're still exposing me even though they know that my body's immune system was positive."

Participants did not explicitly state that the locations they were placed in were above the beryllium standard's action level. In a follow-up communication, a participant explained that there was, in fact, documented evidence of surface contamination. Conflict arose over management not conducting personal air monitoring to determine whether the work locations were in compliance with the action level.

In New Mexico, a single case raised the question of what constitutes a work environment without beryllium exposure under the MRPB. A sensitized worker reported:

"See, I'm beryllium sensitized, too. My employer had to know so ... that I couldn't go into areas like that no more. In turn, I kept my job. Now I work in offices. And I don't go into [beryllium areas] no more."

However, a union official familiar with this case elaborated:

"They set up scaffolds in a beryllium area. How in the hell is that protecting that person? His job duties called for him to set up the scaffolds ... But they took him from one beryllium area and sent him to another beryllium area ... where the third tier contractor or the second tier contractor thinks that he's safer."

Communication among the various contractors and subcontractors about health and safety compliance issues has always been problematic at this DOE site. Evidently, the DOE beryllium standard is no exception.

Beyond the Worksite. No terminations of LPT-positive workers at LANL, Oak Ridge/Y-12 or SNL were alleged. However, the following realistic scenario was considered from the standpoint of a current Oak Ridge/Y-12 employee:

“Once he knows he is sensitive to beryllium that’s going to be in his medical records. And if he loses employment at our place and has to go somewhere else and they want his medical records it’s going to say ‘Look he’s sensitive to beryllium. He’s already got partial lung disease. Do we need to hire him or not?’”

According to other focus group participants, some younger workers at Oak Ridge/Y-12 are eschewing the LPT precisely to avoid this fate. They are waiting until they have built up some retirement security before opting to take the LPT, perhaps in their fifties. Their aim is to avoid potential stigmatization and prolonged joblessness during the decades that typically elapse from initial sensitization to the onset of symptoms. If, in fact, the contractor is not complying with the provisions of the DOE beryllium standard that require reassignment to jobs without beryllium exposure, then opting out of the LPT may strike a reasonable balance among the competing concerns of job retention, family worry, and health protection for some individuals.

Fears of stigmatization were not limited to the LPT test. They extended to the more general case of collateral information which could be revealed by a genetic test:

“It’s also going to probably show that you’re going to get lung cancer in 20 years or whatever. And that’s going to go into your medical records. And then anytime any insurance or any other doctor requests your records, all your medical records including genetic testing ... If they’ve got markers for you going blind or getting Alzheimer’s .. That’s a possibility in the future.”

In fact, the only collateral information now known to be related to the Glu69 marker pertains to an elevated risk of childhood leukemia.[41] However, it is quite possible that

future research will reveal linkages between beryllium susceptibility markers and the risk of certain chronic diseases of adulthood.

Insurability

Threats posed by a genetic test to individuals' insurability were the subject of much comment and strongly held opinions in the worker focus groups. Evidently, threats to insurability have loomed large in workers' prior discussions over the advisability of taking the LPT. A union officer reported:

“One of the things I’ve seen [is] that people ... the reason why they don’t want it is because if they were found to be sensitized ... It becomes a pre-existing issue. And if they were to ever switch employment, it may affect their receiving insurance from their future employer. And that’s why, still to this day, a lot of people will not go and take the LPT test that work in beryllium areas.”

Beryllium workers are vulnerable when they change jobs. They are also vulnerable when they apply for supplemental insurance upon retirement. Among the perceived threats of a positive LPT or genetic test were insurance premiums going “through the ceiling where you couldn’t afford it” and “They will block you off.” Even worse added another: “He’s got it. Let’s cancel his insurance.”

Workers felt that including a genetic test result in one’s medical record was a special risk in two ways. First, this information is routinely transmitted when an application for insurance is made. Second, as noted above, future advances in research may reveal collateral information about the beryllium genetic marker being linked to the risk of other chronic diseases. One worker argued: “It’s going to be held against you if you need some kind of supplemental insurance when you retire.”

A retiree who has been diagnosed with CBD confirmed this threat:

“One thing that I have experienced after being diagnosed with CBD that could also be applied to genetic markers: I can’t get mortgage insurance now because

of my condition. Our union offered \$10,000 free. Life insurance, supplemental insurance. I can't even get that."

As noted above (page 6), the newly enacted Genetic Information Non-Discrimination Act (GINA), a federal law, applies to health insurance. However, it does not cover disability, long-term care, life or mortgage insurance. In sum, the fears and concerns voiced by focus group participants over insurability are well founded.

DISCUSSION AND CONCLUSIONS

Knowledge, Beliefs and Attitudes

Analysis of the transcripts of the five focus groups conducted in New Mexico and Tennessee reveals how current and former beryllium workers and their family members think about genetic testing. Attitudes and beliefs were brought into sharp relief. We observed a disparity in knowledge between workers at ORNL/Y-12 and Los Alamos, most likely due to a functioning beryllium support group at the former site. The lack of available educational programs and materials in Spanish, appropriate for many DOE workers in New Mexico, may be a contributing factor.

The difference in knowledge could guide the development of future educational programs and materials on genetic testing. Los Alamos' participants knowledge is akin to that of currently exposed workers who have not yet contacted a worker health organization nor been placed in a situation where they've had to teach their peers about beryllium. Some misconceptions, such as genotoxicity being the focus of the beryllium genetic marker, could be addressed by future educational programs. The analogies workers used to understand the biological basis of beryllium toxicity, such as allergies to food and agricultural products, may be useful in popular education.

Similarly, the language they used in posing apt scientific questions may be a model for introducing biological concepts with a minimum of technical jargon.

Benefits and Burdens

Overwhelmingly, the perceived benefits of genetic testing were related to autonomous decision-making by workers with respect to career choices for themselves and their children. Some workers would presume that their own test result applies to their children; others explicitly wished testing would be available to their children before entering a trade or facility with beryllium exposure.

As expected, the burdens of testing which provoked the most discussion involved abuse of genetic information by employers. Not even a hypothetical voluntary program, in which test results are disclosed only to the worker, was immune to these concerns. Those enrolled in DOE's "Human Reliability Program" may feel compelled to disclose their genetic test result to their employer. An alternate possibility is that participants were referring to *all* DOE contractor employees who hold security clearances when they opined: "As long as you work for the government ... they're going to find out" and "They're going to do whatever they want."

Additional burdens cited were:

- exploitation of biological materials (i.e., blood, DNA) for scientific purposes beyond the LPT and beryllium susceptibility marker;
- psychosocial stress to family members when a susceptible breadwinner continues to work around beryllium;
- inadequate employer policies for protecting the privacy and dignity of workers on restricted duty.

Also cited was “Superman Syndrome” whereby a worker who tests negative no longer feels obligated to follow precautions to reduce exposure, putting co-workers at peril. This social dynamic -- perhaps a little counterintuitive to health scientists -- could cause a workplace susceptibility testing program to backfire, particularly if the genetic marker is present in a minority of the work force and the test is not highly sensitive.

Venue and Sponsorship of a Voluntary Testing Program

Experience with the “company town” atmosphere in Los Alamos and Oak Ridge was at the root of workers’ emphatic recommendation of complete financial separation of the testing entity from the employer. Involving more than one testing facility was suggested as a way to reduce the potential for untoward interference by a DOE contractor or the government.

Passage of the GINAct in April 2008 has important implications. First, DOE workers are likely to be skeptical that their employers’ compliance with these new protections will be any better than with other federal health, safety and environmental laws. Second, the GINAct substantially narrows the field of actors who may “request, require or purchase” genetic information. Employers are frankly prohibited from doing so; there is no exemption for national security. GINA also proscribes involvement by union and joint-labor management entities.[22] A retiree’s suggestion for a “safety board” established by employers with “workers in charge,” to administer a voluntary testing program, may have been loosely inspired by the Advisory Board on Radiation Worker Health. However, a voluntary testing program sponsored by such a joint labor-management entity would have to be structured with great care so as not to violate GINA.

It is unclear how much flexibility will exist under forthcoming EEOC regulations for employers to accommodate workers who seek out genetic susceptibility testing on their own, voluntarily disclose their own results, and ask to be removed from exposure. As with traditional “light duty,” adopting such policies will require changes in attitude when it comes to the willingness of workers to request reassignments, employers to make them, and co-workers to accept. A challenge for labor-management relations will be to strike a delicate balance among the competing ethical imperatives of privacy, worker autonomy, and health protection. But in light of GINA’s prohibitions, the likelihood of such negotiations occurring seems remote.

Among the actors whose role in the collection of genetic information is not constrained by GINA are:

- University researchers
- Non-profit organizations (other than unions)
- Government researchers
- Direct to consumer testing companies
- Private physicians

Isolated expressions of support were voiced in the focus groups for the involvement of the first three. Direct to consumer testing is ethically suspect.[42, 43] In focus groups held in Tennessee and New Mexico, the most consistent expressions of trust were voiced for family physicians. In 1992 Holtzman forecasted that genetic tests with low acceptance, low PPVs and high potential for insurance discrimination would not be used in population screening programs; such tests would only find use in the “default destination” of family-centered testing.[44] The preference of focus group participants for their family doctor is consistent with this observation.

Those concerned with the responsible use of the genetic test for susceptibility to beryllium may now be enjoying a calm interlude. It seems quite possible that biomedicine's fervent commitment to genetic science, combined with the commercialization of genetic tests, could undermine the formal phased approach to translational research in regional communities of primary care providers. The test has not yet reached the stage of commercialization, despite an April 2000 public affairs newsletter at LANL forecasting "transfer to industry" in a year.[45] Once commercial testing interests enter the picture[46] there may be insufficient time and turf to employ a responsible phased approach of needs assessment, intervention and longitudinal follow-up of outcomes.

In the ensuing sections we consider three possible venues for voluntary, confidential genetic testing: 1) primary care physicians; 2) chest physicians; and 3) former worker programs currently funded extramurally by DOE.

1. Primary Care Physicians. Occupational health advocates and practitioners have long tried to increase the involvement of primary care physicians in recognizing and responding to work-related health concerns. A systematic review of these educational and interventional efforts over three decades does not appear to be available in the literature. Halting progress has been made toward a comprehensive vision[47] of integrating occupational health into primary care through education, access to clinical information, and referral resources.[48, 49] Some of the approaches that have been tried include: curriculum development for medical four year and residency programs;[50-54] training of residents and physicians in history-taking;[55, 56] development of a simple mnemonic for eliciting job health concerns;[57] and continuing education on hazards in local industries.

The modern primary care setting has assets and liabilities as a venue for voluntary genetic testing for susceptibility to beryllium. Family medicine has common foundations with occupational medicine, including the epidemiologic tradition.[58, 59] Indeed, many academic departments of family medicine are home to well-qualified occupational physicians. However, primary care providers are now faced with the need to rapidly develop competencies to determine how to use genetic information most effectively. Until now, most genetic health concerns were seen as rare in the typical primary care patient population. Along with acquiring scientific knowledge of genetic testing, the primary care provider will be faced with the need to evaluate patients with attention to not only medical outcomes, but also ethical and social implications such as medical privacy, confidentiality, duty to warn, family risk, and pre- and post-test counseling and support. The primary care provider will need to respond to patients' questions and potential false hopes[60] stemming from overly optimistic expectations about genetic testing. [61]

There is a rapidly expanding literature on efforts to prepare primary care practitioners for routine use of clinical genetic tests. To students of occupational health there is a strong element of déjà vu: striking similarities to early efforts calling for greater cooperation between the disciplines,[60, 62, 63] defining professional competencies,[64] improving educational resources[42] and training strategies[65, 66], concern with underserved populations,[67, 68] and continuing education programs. Needs assessment methodologies, which promoters of occupational medicine have used to ascertain baseline levels of knowledge among practitioners before intervening, [69, 70] are gaining increasing favor in community-oriented genetics testing.[71, 72]

The needs and concerns of beryllium-exposed workers and families are just now being assessed. Little or no work has been done with primary care practitioners.

Genetic counselors are scarce in rural areas;[67] the number who are also savvy about occupational health is probably infinitesimal. Institutional arrangements in communities to ensure proper use of genetic testing will be difficult to establish in the face of future mercantile pressure by testing companies and some medical specialists, who may be insensitive to the realities of hazards in blue collar occupations.

Doctors not trained in occupational medicine have been known to offer workers little more than aloof advice to simply quit their jobs. A recrudescence of this ill-conceived approach may occur as deterministic thinking about genetic test results sweeps into hospitals and primary care clinics. Genetic counselors, whose discipline takes a scrupulously nondirective approach,[73, 74] are not likely to be a countervailing force.

There is no career track in occupational health that is analogous to genetic counseling. The social structural causes of occupational hazards are not a major emphasis of most social work curricula, although many occupational health clinics do have access to consulting social workers. Disease-specific support groups (like the Beryllium Support Group in Oak Ridge) and stable organizations of injured workers are few and far between.

Who is on the front lines of counseling individual workers and families confronted with complex information and choices about health hazards on the job? Occupational physicians and “technical assistance” providers from union health and safety departments and regional committees on occupational safety and health (COSH groups) carry out this work on a daily basis. Technical assistance providers in occupational health tend to be quite comfortable in advocacy roles and are committed to directed aims of social justice. Primary care practitioners, who have long-term relationships with their patients, may be more comfortable with advocacy-oriented

professionals than with the nondirective genetic counseling profession.[75] However, occupational health physicians and advocates have little experience with genetics, perhaps owing to attitudes established during the 1980's debate over genetic testing. (See Introduction, above).

Absent well-resourced, sustained regional interventions near DOE facilities, a strategy centered on primary care practitioners may be overly ambitious. However, "awareness level" training could be made available at low cost to primary care providers through continuing medical education programs.

2. Chest Physicians. Pulmonary physicians near DOE facilities are the private doctors who are most likely to have had large numbers of beryllium workers in their practices. They will need less preparation than primary care doctors in mastering how the genetic test relates to BeS, CBD, prognosis and treatment. One caveat is that as specialists they are more likely than family physicians to have financial ties to the employer's medical program.

3. Former Worker Programs. Medical surveillance projects funded by DOE extramurally since the mid-1990's have administered the LPT test to tens of thousands of current and former workers. Many of these teams include occupational physicians experienced in pulmonology who are well-versed in beryllium. In addition, the staffs of these programs are likely to include individuals who are committed to protecting the rights of DOE employees. By virtue of their university affiliations, these programs are well-situated to keep abreast of the science of genetic markers, as well as strategies for tailoring genetic counseling protocols to the work environment.

University-based former worker programs have advantages over private physicians with respect to maintaining the privacy of a worker's genetic test result. The files of participants in medical surveillance projects are smaller than patient records in

a private practice. So a genetic test result is less likely to be inadvertently transmitted to anyone other than the worker. Also, university-based programs undergo multiple layers of human subjects review by institutional review boards with a keen eye to the protection of participants' privacy.

Former worker programs that are formally managed by labor organizations may not merely eschew the idea of a voluntary genetic test. Their involvement will be greatly complicated, if not proscribed, by GINA's restrictions on who may "request, require or purchase" genetic information.

Former worker programs not formally affiliated with unions could step into the void. They were conceived as screening programs to conduct a routine battery of tests on large numbers of workers, with little in-depth follow-up. This mission would have to change. A phased approach which first makes the genetic susceptibility test available to *former* workers could serve as the proving ground for educational programs, materials and counseling. Pilot programs structured as community- and labor-oriented partnerships could, over time, cultivate former workers to serve as leaders in later efforts to offer the test on a voluntary, confidential basis to *current* and *prospective* workers. An element of peer counseling might improve the quality of genetic counseling. The involvement of regional primary care providers, chest physicians, genetic counselors and advocacy organizations in shaping these programs would ensure ample resources for follow-up.

No doubt, each pilot project would wrestle anew with the ethical and social issues addressed in this report. Their answers may differ by region of the country. It seems most likely, however, that obtaining funding from an agency other than DOE could be important to beryllium workers across the nation; workers in New Mexico and Tennessee felt that complete financial separation from the employer is essential. Also,

it would be necessary to avoid any boilerplate language, common in federal grants and contracts, which entitles the agency to take custody of project records. However seldom these provisions have been enforced in the past, the critical thinkers we met in our focus groups would likely consider such provisions a “show-stopper.”

Our limited findings indicate that the test’s PPV of 14% is sufficient to provide information which some workers would see as “so important,” in the words of a union official. (See page 23). With research in molecular epidemiology and modeling ongoing, the test’s PPV may increase in value. Should the PPV ever exceed 50%, there won’t be many winning arguments standing in the way of commercial availability of a genetic test. A positive result would mean “more likely than not” the person will develop disease. Those concerned with protecting workers’ rights currently have a window of opportunity to establish partnerships among key community and institutional actors to control genetic testing technology, ensuring that if it is used, it will be used to the benefit, not the detriment, of workers and their families.

RECOMMENDATIONS

	<u>Pages where discussed</u>
1. Provide free LPT testing available to cohabitant relatives of beryllium workers at DOE facilities.	20
2. Develop Spanish language educational programs and materials for beryllium workers and families.	12, 28
3. Monitor development and implementation of GINA regulations to be issued by federal EEOC.	6, 15, 31
4. Seek clarification on appropriate roles available to all union-affiliated entities under GINA regulations in collaborating with other partners to offer a voluntary, confidential genetic test and negotiate over employer policies for voluntary self-removal.	6, 30-1, 36
5. Seek clarification on whether enrollees in DOE's Human Reliability Program are explicitly informed that genetic information need not be self-disclosed during the initial and periodic assessments.	16, 29
6. Evaluate construction workers' attitudes about traditional light duty policies.	17, 31
7. Investigate DOE contractors' compliance with the medical removal protection benefit provisions of the beryllium standard.	15-6, 24-6
8. Monitor developments involving commercialization of a beryllium genetic susceptibility test.	32, 37
9. Monitor national initiatives for electronic medical records, with an eye toward systems for protecting the privacy of genetic data.	26-8, 36
10. Develop low cost, "awareness level" continuing medical education programs on beryllium for primary care physicians near DOE facilities.	32-5
11. Identify former workers who could serve as leaders in partnerships offering education, counseling and possibly a genetic susceptibility test to current and prospective beryllium workers.	36

REFERENCES

1. Rothstein, M.A., *Employee selection based on susceptibility to occupational illness*. Michigan Law Review, 1983. 81: p. 1378-1496.
2. Office of Technology Assessment, *The Role of Genetic Testing in the Prevention of Occupational Disease*. 1983, Washington, D.C.: Government Printing Office. 243.
3. Severo, R., *Genetic tests by industry raise questions on rights of workers*, in *New York Times*. February 3, 1980: New York. p. 1, 36.
4. Murray, T.H., *Genetic testing at work: how should it be used?* Technology Review, 1985: p. 50-59.
5. Draper, E., *Risky Business: Genetic Testing and Exclusionary Practices in the Hazardous Workplace*. 1991, Cambridge: Cambridge University Press. 315.
6. Khoury, M.J., C.A. Newill, and G.A. Chase, *Epidemiologic evaluation of screening for risk factors: application to genetic screening*. American Journal of Public Health, 1985. 75(10): p. 1204-1208.
7. Rothstein, M.A., *Keeping your genes private*. Scientific American, 2008. 299(3): p. 64-69.
8. Samuels, S.W., *On the ethical practice of environmental and occupational medicine*, in *Environmental and Occupational Medicine*, W.N. Rom, Editor. 1998, Lippincott-Raven Publishers: Philadelphia, PA. p. 1795-1805.
9. Samuels, S.W., *A moral history of the evolution of a caste of workers*. Environmental Health Perspectives, 1996. 104(S5): p. 991-998.
10. Silver, K. and R.R. Sharp, *Ethical considerations in testing workers for the -Glu69 marker of genetic susceptibility to chronic beryllium disease*. Journal of Occupational and Environmental Medicine, 2006. 48(4): p. 434-443.
11. Saltini, C., *A genetic marker for chronic beryllium disease*, in *Biomarkers and Occupational Health: Progress and Perspectives*, M.L. Mendelsohn, Peeters, J.P., and Normandy, M.J., Editor. 1995, Joseph Henry Press: Washington, D.C. p. 293-303.
12. Ashford, N.A., et al., *Monitoring the Worker for Exposure and Disease: Scientific, Legal and Ethical Considerations in the Use of Biomarkers*. The Johns Hopkins Series in Environmental Toxicology, ed. Z. Annau. 1990, Baltimore, MD: Johns Hopkins University Press. 224.
13. Weston, A., et al., *Racial differences in prevalence of a supratypic HLA-genetic marker immaterial to pre-employment testing for susceptibility to chronic beryllium disease*. American Journal of Industrial Medicine, 2002. 41: p. 457-465.
14. Weston, A., *Presentation to the Central Beryllium IRB*. 2005: Knoxville, TN.
15. Snyder, J.A., et al., *Impact of negatively charged patches on the surface of MHC class II antigen-presenting proteins on risk of chronic beryllium disease*. Journal of the Royal Society Interface, 2008. 5(24): p. 759-58.
16. Tan-Wilhelm, D., et al., *Impact of a worker notification program: assessment of attitudinal and behavioral outcomes*. Am J Ind Med, 2000. 37(2): p. 205-13.
17. McCanlies, E., et al. *Educating beryllium workers about genetic information. Poster presentation*. in *American Public Health Association*. 2004. Washington, D.C.
18. Lomax, G.P., *Evaluating Genetic Testing for Susceptibility to Occupationally-Induced Disease: A Case Study of Chronic Beryllium Disease*. Doctoral dissertation, *Graduate Division*. 2002, University of California, Berkeley: Berkeley, CA. p. 144.

19. Silver, K. and H. Romero, *Playing with Fire on a Remote Plateau: The Coming of Genetic Susceptibility Testing of Workers at Los Alamos National Laboratory*, in *Genes, Cancer and Ethics in the Work Environment*, S.W. Samuels, Editor. in press, OEM Press: Beverly, Mass.
20. Samuels, S.W., *An alternative understanding of aggression in the work environment*. *European Journal of Oncology*, 2000. 5(S2): p. 55-61.
21. Levy, D.E., E.J. Youatt, and A.E. Shields, *Primary care physicians' concerns about offering a genetic test to tailor smoking cessation treatment*. *Genetics in Medicine*, 2007. 9(12): p. 842-9.
22. *Genetic Information Nondiscrimination Act of 2008*, P.L. 110-233. 42 *US Code* 2000ff, 2008. p. 42.
23. Slaughter, L.M., *The Genetic Information Nondiscrimination Act: Why your personal genetics are still vulnerable to discrimination*. *Surgical Clinics of North America*, 2008. 88: p. 723-738.
24. Hudson, K.L., M.K. Holohan, and F.S. Collins, *Keeping pace with the times - The Genetic Information Nondiscrimination Act of 2008*. *New England Journal of Medicine*, 2008. 358(25): p. 2661-2663.
25. Locke, S.S., *The incredible shrinking protected class: Redefining the scope of disability under the Americans with Disabilities Act*. *University of Colorado Law Review*, 1997. 68: p. 107.
26. Rothstein, M.A., *Genetics and the work force of the next hundred years*. *Columbia Business Law Review*, 2000. 2000(3): p. 371-402.
27. Larroca, J.W., *Toyota Motor Manufacturing, Kentucky, Inc. v. Williams: Disabling the Americans with Disabilities Act*. *Journal of Contemporary Health Law and Policy*, 2002. 19: p. 363.
28. Sheil, K.M., *The Americans with Disabilities Act: Are your wrists protected?* *The Journal of Corporation Law*, 1998. 23: p. 325.
29. Lomax, G., *Chevron v. Echazabal: A sobering decision for environmental health research*. *Environmental Health Perspectives*, 2002. 110(5): p. A504-5.
30. Earley, C.L. and L.C. Strong, *Certificates of confidentiality: a valuable tool for protecting genetic data*. *American Journal of Human Genetics*, 1995. 57: p. 727-731.
31. Lutz, K.F., et al., *Uses of certificates of confidentiality in nursing research*. *Journal of Nursing Scholarship*, 2000. 32(2): p. 185-188.
32. Kinney, A.Y., et al., *Genetic testing for colorectal carcinoma susceptibility: focus group responses of individuals with colorectal carcinoma and first-degree relatives*. *Cancer*, 2001. 91(1): p. 56-65.
33. Ryan, E.L. and C.S. Skinner, *Risk beliefs and interest in counseling: focus-group interviews among first-degree relatives of breast cancer patients*. *Journal of Cancer Education*, 1999. 14(2): p. 99-103.
34. Kreiss, K., et al., *Epidemiology of beryllium sensitization and disease in nuclear workers*. *American Review of Respiratory Disease*, 1993. 148: p. 985-991.
35. U.S. Department of Energy, *Human Reliability Program*. *Code of Federal Regulations*, 2008. Title 10, Part 712.
36. Dobson, M. and R. Williamson, *Indigenous peoples and the morality of the Human Genome Diversity Project*. *Journal of Medical Ethics*, 1999. 25(2): p. 204-8.
37. Tsosie, R., *Cultural challenges to biotechnology: Native American genetic resources and the concept of cultural harm*. *Journal of Law, Medicine and Ethics*, 2007. 35(3): p. 396-411.

38. Welch, L., et al., *Screening for beryllium disease among construction trade workers at Department of Energy nuclear sites*. American Journal of Industrial Medicine, 2004. **46**(3): p. 207-18.
39. Lang, L., *Beryllium: a chronic problem*. Environmental Health Perspectives, 1994. **102**(6-7): p. 1-7.
40. U.S. Department of Energy, *Chronic beryllium disease prevention program; final rule*. Federal Register, 1999. **64**(235): p. 68854-68914.
41. Taylor, G.M., et al., *Genetic susceptibility to childhood common acute lymphoblastic leukaemia is associated with polymorphic peptide-binding pocket profiles in HLA-DPB1*0201*. Human Molecular Genetics, 2002. **11**(14): p. 1585-1597.
42. Cho, M.K., M. Arruda, and N.A. Holtzman, *Educational material about genetic tests: does it provide key information for patients and practitioners?* American Journal of Medical Genetics, 1997. **73**(3): p. 314-20.
43. Wasson, K., E.D. Cook, and K. Helzlsouer, *Direct-to-consumer online genetic testing and the four principles: an analysis of ethical issues*. Ethics in Medicine, 2006. **22**(2): p. 83-91.
44. Holtzman, N.A., *The diffusion of new genetic tests for predicting disease*. FASEB Journal, 1992. **6**(10): p. 2806-12.
45. Anon, *New tests will help predict, diagnose chronic beryllium disease*, in *Dateline Los Alamos*. April 2000. p. 1-4.
46. Burke, W., *Contributions of public health to genetics education for health professionals*. Health Education and Behavior, 2005. **32**(5): p. 668-75.
47. Paul, M. and L. Welch, *Improving education and resources for health care providers*. Environmental Health Perspectives, 1993. **101**(Suppl 2): p. 191-7.
48. Michas, M.G. and C.U. Iacono, *Overview of occupational medicine training among U.S. family medicine residency programs*. Family Medicine, 2008. **40**(2): p. 102-6.
49. LaDou, J., *The rise and fall of occupational medicine in the United States*. American Journal of Preventive Medicine, 2002. **22**(4): p. 285-95.
50. Yassi, A., et al., *Evaluating medical performance in the diagnosis and treatment of occupational health problems: a standardized patient approach*. Journal of Occupational Medicine, 1990. **32**(7): p. 582-5.
51. Frazier, L.M., et al., *Teaching occupational and environmental medicine in primary care residency training programs: experience using three approaches during 1984-1991*. American Journal of Medical Science, 1991. **302**(1): p. 42-5.
52. Frazier, L.M., et al., *Developing occupational and environmental medicine curricula for primary care residents: project EPOCH-Envi. Educating Physicians in Occupational Health and the Environment*. Journal of Occupational and Environmental Medicine, 1999. **41**(8): p. 706-11.
53. Buranatrevedh, S., *A need assessment study of occupational health curriculum for Thai medical students*. Journal of the Medical Association of Thailand, 2007. **90**(9): p. 1894-907.
54. Sokas, R.K., et al., *Environmental medicine: its introduction into a medical school primary care requirement*. Medical Education, 1993. **27**(5): p. 410-5.
55. Orris, P. and S. Baron, *Occupational medicine: a role for the primary care physician*. Hospital Practice, 1983. **18**(3): p. 195-7.
56. Frank, A.L., *Approach to the patient with an occupational or environmental illness*. Primary Care, 2000. **27**(4): p. 877-94.

57. Schuman, S.H. and W.M. Simpson, *WHACS your patients*. Journal of Occupational and Environmental Medicine, 1999. **41**(10): p. 829.
58. Frumkin, H., *Occupational and environmental medicine and primary care*. Primary Care, 2000. **27**(4): p. 813-30.
59. Fried, R.A., *The family physician looks at occupational health information*. American Journal of Preventive Medicine, 1987. **3**(2): p. 110-5.
60. Burke, W., *Genetic testing in primary care*. Annual Review of Genomics and Human Genetics, 2004. **5**: p. 1-14.
61. Houry, M.J., et al., *Challenges in communicating genetics: a public health approach*. Genetics in Medicine, 2000. **2**: p. 198-202.
62. Burke, W. and J. Emery, *Genetics education for primary-care providers*. Nature Reviews in Genetics, 2002. **3**(7): p. 561-6.
63. Emery, J. and S. Hayflick, *The challenge of integrating genetic medicine into primary care*. British Medical Journal, 2001. **322**(7293): p. 1027-30.
64. Engstrom, J.L., et al., *Genetic competencies for health care professionals in primary care*. Journal of Midwifery and Womens Health, 2005. **50**(3): p. 177-83.
65. Burke, W., et al., *Genetics in primary care: a USA faculty development initiative*. Community Genetics, 2002. **5**(2): p. 138-46.
66. Lose, E.J., *The emerging role of primary care in genetics*. Current Opinion in Pediatrics, 2008. **20**(6): p. 634-8.
67. Kelly, K.M., et al., *Information seeking and intentions to have genetic testing for hereditary cancers in rural and Appalachian Kentuckians*. Journal of Rural Health, 2007. **23**(2): p. 166-72.
68. Shields, A.E., W. Burke, and D.E. Levy, *Differential use of available genetic tests among primary care physicians in the United States: results of a national survey*. Genetics in Medicine, 2008. **10**(6): p. 404-14.
69. Abbritti, G., et al., *Needs, education and accreditation in occupational medicine in Italy*. International Archives of Occupational and Environmental Health, 2005. **78**(1): p. 75-8.
70. Wheat, J.R., et al., *Strategy to increase agricultural medicine practice: an exploratory study to predict interest among generalists*. Journal of Rural Health, 2002. **18**(1): p. 18-24.
71. Scheuner, M.T., P. Sieverding, and P.G. Shekelle, *Delivery of genomic medicine for common chronic adult diseases: a systematic review*. JAMA, 2008. **299**(11): p. 1320-34.
72. Trinidad, S.B., et al., *Educational needs in genetic medicine: primary care perspectives*. Community Genetics, 2008. **11**(3): p. 160-5.
73. Stehney, M., *Legacy of the American eugenics movement: implications for primary care*. Primary Care, 2004. **31**(3): p. 525-41.
74. Resnick, D.B., *Genetic testing and primary care: a new ethic for a new setting*. New Genetics in Society, 2003. **22**(3): p. 245-56.
75. Martin, J.R. and A.S. Wilikofsky, *Genetic counseling in primary care: longitudinal, psychosocial issues in genetic diagnosis and counseling*. Primary Care, 2004. **31**(3): p. 509-24.

TABLE 1. NUMBERS OF PARTICIPANTS IN FOCUS GROUPS

	<u>Locale</u>		
<u>Target Group</u>	Espanola, NM	Albuquerque, NM	Knoxville, TN
Workers' Focus Group	11	5	12
Family Members' Focus Group	5*		6*

*predominantly family members, but some workers included

TABLE 2. DEMOGRAPHIC DATA

	<u>New Mexico</u>	<u>Tennessee</u>
Total no. participants	21	18 [§]
Age	57.0 (±13.5)	58.9(±8.7)
Years since first exposure	14.7 (±7.6)	20.8(±7.9)
	<u>All Participants</u>	
Diagnosis	BeS	5 (13.5%)
	CBD	5 (13.5%)
	Neither	9 (24.3%)
	No answer	18 (48.6%)
Ethnicity	African-American	4 (10.8%)
	Hispanic	15 (40.5%)
	White	18 (48.6%)
Gender	Male	29 (78.3%)
	Female	8 (21.6%)
Educational Attainment	Not college graduate	29 (78.3%)
	College or higher	8 (21.6%)

[§] Two Tennessee participants did not submit demographic questionnaires. So the numbers and percentages in this table are based upon 16 participants in Tennessee.

TABLE 3. POSSIBILITIES FOR AUTONOMOUS DECISION-MAKING

Current Workers

“..informed ... can make a conscious decision.”

“Knowledge is power.” “...know what you’re up against.”

“...find another trade. Do something else.”

“They might want to be an alfalfa farmer instead...”

Former Workers

“If I would have had ... another job in my earlier years, I would have taken it. Without having to end up...”

“I would steer my children away...”

“I’m beryllium sensitized... so my kid would be susceptible to it. I’d rather him pick another career...”

TABLE 4. BURDENS OF TESTING: POTENTIAL ABUSE BY EMPLOYERS

<u>Private Sector and Generic Employers</u>
“They’ll get rid of you.”
“My concern is how business is using things for their benefit. It could be used in an improper way. It’s rough times out there, especially in the private sector.”
“It’s like a Big Brother thing. The corporations are owned by the insurance companies. That might keep me from getting the test.”
“We know what the industry would like to do.”
<u>Contractors at Government-Owned Nuclear Facilities</u>
“They’re ruthless. It’s just beyond anyone’s wildest dreams.”
“We can have the best DNA test in the world. But if there’s no accountability we’ve got nothing. Nothing.”
[extant special program] “...they can go into your medical records ...your bank accounts. And you have to let ‘em know what kinds of drugs you’re doing. They are in your personal life big time. That’s when you deal with high risk stuff.”
“I’ve worked for the government. I’m very skeptical as to whether it will be done the way it should be done.”
“We don’t really trust the government.”
“This test here will probably be entered into a data base.” “Who controls the data base?” “The FBI will have all of this.”
“Maybe I’ve got Big Brother syndrome... because I don’t trust anything anybody in the higher echelon [of] government, corporations or what anybody says.”
“Martin Powers from Brush-Wellman ... stated [in 1994] if we could take that small percentage and spring them out, we could eliminate the disease. Eliminate the marketing problem that comes with having a toxic material. And we could begin doing away with some of those very expensive control measures.”
“I don’t think anybody at Y-12 would trust the company not to misuse it. Or withhold the findings.”
“It’s an ethics issue. And they’ve been unethical for so long.”
“Look what the Germans did with genetic engineering back in the 1930’s. I know that’s an extreme. But ... as long as I know what they’re going to do with this information it’s fine. But what is it going to be used for?”
“The younger kids don’t realize when they go there to work, especially at Y-12 is that Medical is there just to protect the company. It is not there to protect you. They’re just trying to get their legal obligation to where they can cover their own a—and the heck with you ... We’ve had cases where people have x-rays and they showed cancers – lung cancers – and they’ve not told the employee until years later.”
“Los Alamos is a company town. They all talk to one another when something like this comes up.”

APPENDIX A



Centers for Disease Control
and Prevention (CDC)
Atlanta GA 30333

CONFIDENTIALITY CERTIFICATE

Issued to

Employees of

East Tennessee State University

and Other Participants

conducting research known as

GENETIC TESTING FOR BERYLLIUM:
WORKER KNOWLEDGE, BELIEFS AND ATTITUDES

Cooperative Agreement # U54-OH008307
Grant # 06-3-PS from the Center to Protect Workers Rights

The purpose of the project is to examine the knowledge, beliefs, and attitudes of beryllium-exposed workers regarding genetics testing. Using focus groups and telephone interviews, researchers will document the opinions of beryllium-exposed workers and family members.

In accordance with the provisions of Section 301(d) of the Public Health Service Act (42 U.S.C. § 241(d)) this certificate is issued to protect the privacy of research subjects by withholding their identities from all persons not connected with the research.

Under authority vested in the Secretary of Health and Human Services under that section, all persons who

- (1) are employed by East Tennessee State University and their contractors and cooperating agencies; and
- (2) have, in the course of that employment, access to the information which would identify individuals who are the subjects of a research project entitled "Genetic Testing for Beryllium: Worker Knowledge, Beliefs and Attitudes" are hereby authorized to protect the privacy of the individuals who are the subjects of that research by withholding their names and other identifying characteristics from all persons not connected with the conduct of that research, with the exceptions and limitations set forth below.

As provided in Section 301(d) of the Public Health Service Act (42 U.S.C. § 241(d)),

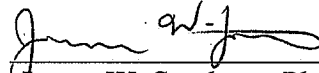
“Persons so authorized to protect the privacy of such individuals may not be compelled in any Federal, State, or local civil, criminal, administrative, legislative, or other proceedings to identify such individuals.”

The following conditions apply to the protection provided under this certificate:

- (1) This certificate does not authorize East Tennessee State University or their contractors or cooperating agencies to refuse to reveal identifying information concerning research subjects if any of the following conditions exist:
 - (a) The subject (or, if he or she is legally incompetent, his or her guardian) consents in writing to disclosure of identifying information.
 - (b) Authorized personnel of the United States Department of Health and Human Services request such information for audit or program evaluation of the research project, or for investigation of East Tennessee State University or their contractors or cooperating agencies in carrying out the research project.
 - (c) Release is required by the Federal Food, Drug, and Cosmetic Act (21 U.S.C. §§ 301 et seq.) or regulations promulgated thereunder (Title 21, Code of Federal Regulations).
- (2) This certificate requires that there be no disclosures of identifying characteristics of research subjects in any Federal, State, or local civil, criminal, administrative, legislative, or other proceedings to compel disclosure of the identifying characteristics of research subjects, except as provided for in paragraph (1) above.
- (3) The confidentiality certificate does not govern the voluntary disclosure of identifying characteristics of research subjects.
- (4) This certificate does not represent an endorsement of the research project by the Department of Health and Human Services.
- (5) All research subjects in the project will be given a fair, clear explanation of the protection this certificate affords, and of the limitations and exceptions to the protection.

- (6) This certificate is effective upon issuance and will expire at the end of March 2012, or sooner if the holder is notified of cancellation in accordance with the procedures set out in 42 C.F.R. § 2a.8. The protection afforded by this certificate of confidentiality is permanent (including after death) for persons who participated as subjects in the research during any time the certificate was in effect.

Date: 3/12/08



James W. Stephens, Ph.D.
Associate Director for Science, CDC



Centers for Disease Control
and Prevention (CDC)
Atlanta GA 30333

March 12, 2008

Ken Silver, DSc, SM
Department of Environmental Health
East Tennessee State University
P.O. Box 70682
Johnson City, TN 37614

Dear Dr. Silver:

I am happy to send you the certificate of confidentiality for "Genetic Testing for Beryllium: Worker Knowledge, Beliefs and Attitudes."

Please be sure that the informational statement given to participants accurately states the intended uses of personally-identifiable information and the confidentiality protections, including the protection provided by the certificate of confidentiality, with its limitations and exceptions.

It was noted that the study's approved consent form did not contain the phrase that researchers "must report suspected cases of child abuse." The CDC/NIOSH Attorney-Advisor agreed that under the circumstances of this study, we do not have to insist on inclusion of that language in the consent form. However, you and your research staff are reminded that if you learn of child abuse or have a reasonable suspicion of child abuse based on information learned in focus groups in either Tennessee or New Mexico, you are required by laws in both states to report the information to the appropriate authorities.

May I ask that you advise me of any situation in which the certificate is employed to resist disclosure of information in legal proceedings. I am at the Centers for Disease Control and Prevention, (CDC), Mailstop D-74, Atlanta, Georgia 30333. My telephone number is (404) 639-4791, fax (404) 639-3060. Internet: ccoble@cdc.gov

If attorneys for East Tennessee State University wish to discuss the use of the certificate, they may contact the Deputy Associate General Counsel to CDC, Ms. Paula L. Kocher, at (404) 639-7200.

If you have any questions, or if we can otherwise help, please call.

Sincerely yours,

Cheryl A. Coble

Cheryl A. Coble, MMSc
CDC Acting Confidentiality Advisor
Office of the Chief Science Officer

APPENDIX B

Actors and authorities

- attorneys
- Beryllium industry in general
- Big Brother
- Brush-Wellman
- BWXT
- contracting rules
- Government
 - CDC
 - DOE~NNSA
 - Inspector General
 - NIOSH
 - NMED
 - OSHA
- Journalists
- Los Alamos Nat Labs ~LANL
 - its contract with DOE~NNSA
- Nazis
- Research Teams
 - NJC
 - Queens College
 - Univ Colorado
 - VVM (Alberdn)
- sub_contractors ~construction busine
- unions
 - rank and file
 - right to work
- Watchdog groups
- Collateral uses
- Data Handling
 - Censored data
 - Court-ordered disclosure
 - Data privacy
 - Inclusion in medical record
 - Lost records
 - Proprietary interest in DNA
 - Record retention
- Disease compensation

Beryllium Basics

- analogies b/wr other diseases and CBD
- BES testing
- BES~CBD connection 2
- Bloodborne (specious)
- Buildings contaminated
- CBD prognosis
- Dose response
- epi data
- Industrial hygiene measurements
- Inter-individual variability
- job titles at risk or exposed
- Latency
- Medical Removal Protection Benefits
- mis_diagnosis of CBD
- routes of exposure
- smoking and CBD
- symptoms of CBD
- Clinical Encounters
 - Biopsies for diagnosis
 - DOL surveillance ~Denver, UPenn~
 - Family members' access
 - Former worker program JHU
 - Los Alamos local medical community
 - Medical Surveillance ~employer
 - Personal physician
 - Queens College
 - Treatments
- DNA
 - genotoxicity ~very damage - specious
 - heritability of suscept~ trait ~vail
 - in general
 - knowledge of DNA
 - Risk Numbers
 - lay
 - official
 - Over-interpretation
 - positive predictive value ~ppv~

Gene testing programs

- Accuracy of reporting of test results
- Accuracy of testing
- Analogies
 - to asbestos
 - to breast cancer
 - to drug testing
 - to light duty work
 - to respirator fit shaving
- Conflict of interest
- Cost of testing & Sponsorship
- Decision-making body
- Eligibility for testing
- Enforcement of rights and laws
- Guidelines needed
- Informed consent
- Interpretation of test results
- Legislation needed
- Manda-voluntariness of testing
 - mandatory
 - conditions of manda-voluntariness
 - voluntary
- Questions re ~gene testing
- Separation
- Testing agency
- Testing venue
- Timing of test pre- post- employment
- Trust
 - Un~desirability of testing
 - cloning abuse
 - collateral information
 - earlier diagnosis
 - prediction
 - Pre-employment screening
 - Psychosocial stress
 - therapies - prospects for
- Worker education
- Worker incentive

[-] Implications of Testing	
[-] "The Common Good"	
[-] Abuse "generic" by employers	
[-] Alternative employment	
[-] Assumption of Risk	
[-] Benefits of testing	
[-] added protection	2
[-] autonomy	2
[-] health decisions	2
[-] longevity	2
[-] medicolegal_ proving causation	1
[-] prevention	1
[-] right to know	1
[-] Variability in co-workers explained	0
[-] Civil liberties	
[-] Discrimination	
[-] post-employment	2
[-] pre-employment	2
[-] Disease compensation	
[-] Employer Notification	
[-] Employer notification of test	
[-] Employer Role	
[-] Exposure controls de-emphasized	
[-] Family notification of test	
[-] Insurability	
[-] Liability	
[-] Long-term unemployment	
[-] Other burdens of testing	
[-] Superman syndrome	1
[-] Pandora	
[-] Pre-existing condition	
[-] Removal _ Reassignment based on test	
[-] Retiree perspective	
[-] Retrospective remorse over unavailability of genetic test at	
[-] Self-non_ disclosure of test results	
[-] Worker notification of test results	
[-] Faith and spirituality	

[-] Name	
[-] General OS&H	
[-] Protections	
[-] administrative controls	
[-] behaviors	
[-] controls - scrubbers, scaffolds	
[-] Monitors	
[-] PPE and clothing	
[-] radiation dosimetry	
[-] work practices	
[-] Worker Educn non-genetic	
[-] Safety	
[-] future	
[-] past	
[-] Beryllium exposures	
[-] Radioactive materials	
[-] present	
[-] radioactive materials	
[-] Social Context	
[-] Accountability	
[-] company town	
[-] economic disparities	
[-] environmental contamination	
[-] ethnic communities	
[-] small communities	
[-] family	
[-] Gossip	
[-] Labor-management relations	
[-] management attitudes	
[-] Misinformation	
[-] national security secrecy	
[-] paycheck vulnerability	
[-] political economy of os&h	
[-] Restricted duty	
[-] retaliation	
[-] Total Information Program enrollment in	1
[-] workers' risk perceptions	3

APPENDIX C

Beryllium Health Forum ♦ Espanola, NM
Saturday, June 28 9:00 AM to 2:00 PM
Contact: Paul Montoya (753-6786) or Ken Silver (423-439-4542)

1st Location: JCI Building (1027 N. Railroad Ave., just south of Angelina's Restaurant)

9 AM Dr. Laurence Fuortes, Professor of Occupational and Environmental Health, University of Iowa

10 AM Panel: Ask the Experts

11 AM Update on ETSU Genetic Testing "Knowledge, beliefs and attitudes...." study: Dr. Gary Kukulka, Professor of Family Medicine, East Tennessee State University

2nd Location: Northern New Mexico College "ITV" Classroom (Lunch, ordered in AM)

12 noon Teleconference with Oak Ridge beryllium worker advocates in Knoxville, TN & Guest Speakers:

- Lisa Barker, National Jewish Medical and Research Center, Denver**
 - **Beryllium biorepository**
 - **Patient support activities**

Dr. Laurence Fuortes, University of Iowa: Case Presentations

2 PM Conclude

Made possible by a generous contribution from Alex and Adeline Smith of Albuquerque.

APPENDIX D

Genetic Susceptibility Testing for Beryllium: Against Ken Silver and Richard Sharp

&

Worker Knowledge, Beliefs and Attitudes
Ken Silver and Gary Kukulka

ETSU

Glu69 Recap

- Glu69 Marker
 - Low specificity
 - Moderate to high sensitivity
 - PPV varies with disease & allelic prevalence
e.g., If prev. = 5%, 50:50 Anglo:Hispanic -> PPV=12%
- (-) responsibility shifted to worker
- (-) possible inattention to I.H. controls
- (-) AEC-DOE history of disrespect for workers' rights

Silver and Sharp, JOEM 2006

Implicit Value Assumptions

Choose a biomarker with high to achieve

Sensitivity ⇒ efficiency

Specificity ⇒ fairness

PPV ⇒ autonomy

Positive Predictive Value (PPV)

PPV = the percentage of subjects testing positive who will go on to develop the disease. Depends on:

- allelic frequency
- disease frequency
- sensitivity
- specificity

Weston et al of NIOSH (2002):

If 5% disease frequency □ PPV = 8.3-14.3%

If 15% disease frequency □ PPV = 24.9-43.0%

Genetic Susceptibility Markers

What's New?

- Weston (2005): rare alleles with PPV ~ 100%
- Snyder et al (2008): physical biochemistry of metal-protein interactions consistent with molecular epidemiologic findings


Genetic Information Nondiscrimination Act

(P.L. 110-233)

- Title II: Employment
 - Covers: employers, employment agencies, unions, labor-management training programs
 - Prohibits
 - requesting, requiring or purchasing GI about employee or family member
 - using GI in hiring, firing, job assignments and protections
 - Remedies and Enforcement
 - EEOC, AG, private right of action for disparate treatment
 - Damages capped at \$300K
 - EEOC regulations forthcoming

(How) To Test or Not to Test?

That is the Question!



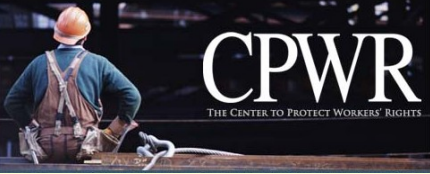
Focus Groups at Los Alamos and Oak Ridge:

- BeS and CBD former and current employees
- family members


& Follow-up telephone interviews

Analysis of transcripts using qualitative NVivo software

Grounded Theory Methodology







- This research is made possible by the Small Studies Program at the Center to Protect Workers' Rights (CPWR) as part of a cooperative agreement with NIOSH.



Acknowledgements

- Kathleen Rayman, PhD and Richard Sharp, PhD
- James Gorniewicz, Patti Dugger and Susan Gardner
- Hilario Romero, PhD, Paul Montoya, Daniel Valerio, Community leaders
- Richard Espinosa and Bob Baskus, Labor Leaders
- Debra Begel, Sound Tech


Gary Kukulka, PhD
 Assistant Professor
 Dept. of Family Medicine
 Quillen College of Medicine
 ETSU
 Johnson City, TN
kukulka@etsu.edu

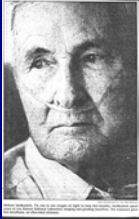




ANSEL ADAMS

- June 2007 Focus Groups (Española, NM)
 - 11 beryllium employees
 - 4 family members + 1 employee
- August 2007 Focus Group (Albuquerque, NM)
 - 4 employees + 1 family member
- April 2008 Focus Groups (Knoxville, TN)
 - 12 employees
 - 6 family members



Advocacy Then Access

EEOICPA

- Part B: \$150,000 plus lifetime medical
 - cancer
 - CBD
- BeS: lifetime medical monitoring (no \$)
- Part E (2004) : substitute for state workers' compensation
 - "consequential" illnesses
 - wage loss, impairment, survivor benefits
 - "other" toxic substances
- exclusive remedy


No mention of "genetic" in statute or legislative history



A Tale of Two Counties

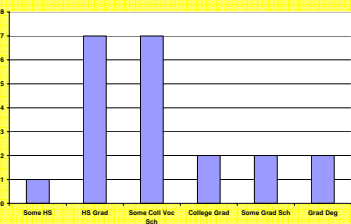
Indicator	Los Alamos County	Rio Arriba County
Technical Staff Members \$\$\$	78.6%	3.8%
General Support Staff \$	32.4%	48.9%
Unemployment	2.1%	11.8%
Poverty Status	2.4%	27.5%
H.S. Drop-out Rate	1.9%	15.9%
Median HH Income	\$54,801	\$18,373
Medicaid Recipients	1.8%	27.5%
Cirrhosis SMR (-NM)	17	320
Suicide SMR (-NM)	114	246

Demographics



Age: 57.0 (range 35-90)
 Since 1st exposure: 14.7 yrs (± 7.0)
 Ethnicity: 71% (15/21) Hispanic
 Family members: 23% (5/21)
 Ever worked with Be: 18 (11 current)

Trades & "Techs"
 ✓ steamfitters
 ✓ operating engineers
 ✓ electricians
 ✓ carpenters
 ✓ sheet metal workers
 & never-unionized UC-LANL "technicians"



Attainment	Count
Some HS	1
HS Grad	7
Some Coll Voc Sch	7
College Grad	2
Some Grad Sch	2
Grad Deg	2

- ### Guideline Questions
- Should workplace genetic testing be offered to:
 - all
 - some;
 - optional or mandatory?
 - Benefits and burdens
 - How would individuals benefit? Any burdens?
 - Factors which would increase or decrease your likelihood of pursuing testing
 - Responses to positive/negative results

- ### Key Issues
- Sponsorship
 - Venue
 - Voluntariness
 - Confidentiality
 - Response to results

Does this genetic test...

...Tell me something I don't know?

<u>No genetic test</u>	<u>Glu69 genetic test</u>
Disease prevalence ≈ 5%	PPV ≈ 14%

Results

- Knowledge and Beliefs
 - General
 - Heritability or genotoxicity?
- Benefits and Burdens
- Attitudes on
 - privacy
 - voluntariness
 - venue and sponsorship
 - Family issues
 - Response to results
 - Risk numbers

Arguments Against

1. Insufficient **education** to date of workers and families
2. de facto violations of **privacy** in a "company town"; no "accountability"
3. No consensus on **sponsorship and venue**
4. **Insurability**
5. No policies yet on
 - **Self-disclosure**
 - Prophylactic **removal**
6. "**Superman syndrome**" > IH protections

Knowledge and Beliefs

- "When they check you for sensitivity, what's the difference between that and genetics?"
- "If there is a group of people working together with beryllium only maybe four are sensitized to it ... So is there an explanation for that?"

Knowledge and Beliefs (cont'd)

- "We don't have no idea of what a genetic test is. We don't know if they take blood, or your blood pressure. Or if they take a shot in your eye. Your urine? We have no idea."
- "Genetic testing is like DNA, right? Like solving cases. You see all this stuff on TV nowadays. It's like crimes and CSI."
- "I still say education is the number one priority."

Heritability or Genotoxicity?

- "My children have the same genes as I do. So they're probably going to be sensitive to it if I was."
- "I'd say mandatory because of the genetic. I'm thinking of a child that hasn't been born yet."
- "If it alters your genetic material, that would alter your future generations."

Benefits

Of a negative test result

The satisfaction of knowing I don't have it."
"It would ease the mind."

Of a positive test result: AUTONOMY

"You are informed. And you can make a conscious decision."
"Knowledge is power."

"It's good to know what you're up against."

"If you don't have to be exposed to it, find another trade. Do something else."

"Give them a choice. They might want to be an alfalfa farmer instead of a Los Alamos worker."

Former workers who are LPT positive

"If I would have had ... another job in my earlier years, I would have taken it. Without having to end up..."

"It's probably too late for me, but I would steer my children away from something bad."

"I'm beryllium sensitized..., so my kid would be susceptible to it. I'd rather him pick another career..."

Benefits (cont'd)

Causation

"To prove that you have a problem is so difficult. To prove your case."

Early Detection

"It's like detecting a cancer before you get it. The sooner you know, maybe you'll get cured. I'm all for it."

Burdens

Angst

- "... the **mental anguish** you go through..."
- "If I told my wife or family members that I work in an exposed area **they would be worried** day in and day out."
- "It's **like a roller coaster** for your family."

Exploitation of Biological Materials

- "If they **used the DNA for something else.**"
- "They take blood – like four, five, six vials of blood. And **you never know what they did with it** or anything."

Burdens (cont'd)

- "It becomes a pre-existing issue. It may affect them receiving **insurance** from their future employer."
- "You can have '**Superman Syndrome.**'"
- "We can have the best DNA test in the world. But if there's **no accountability** we've got nothing. Nothing."

Adverse Actions by Employers

- "They'll **get rid of you.**"
- "They're **ruthless.** It's just beyond anyone's wildest dreams."
- "My concern is how business is using things for their benefit. It could be **used in an improper way.** It's **rough times out there,** especially in the private sector."

vs.

- "You gotta understand Los Alamos. They've got jobs all over the place. So if you can't fit into beryllium they've always got a job for you."

Guideline Questions

- Should workplace genetic testing be offered to:
 - all
 - some
 - optional or mandatory?
- Benefits and burdens
 - How would individuals benefit? Any burdens?
- Factors which would increase or decrease your likelihood of pursuing testing
- Responses to positive/negative results

Privacy Concerns

- "Privacy policies have to be in place."
- "It should be like 'Don't ask, don't tell.'"
- "Los Alamos is a **company town.** **They all talk to one another** when something like this comes up."
- [extant special program] "...**they can go into your medical records** ...your bank accounts. And you have to let 'em know what kinds of drugs you're doing. They are in your personal life big time. That's when you deal with **high risk stuff.**"
- "Everybody knows... because he's not working with the beryllium. So **how do you really protect that person's privacy?**"
- "Let's say the guy gets put on light duty. Well, a lot of the other **co-workers will give him s--t.**"

Privacy (cont'd)

- "I've worked for **the government**. I'm very **skeptical** as to whether it will be done the way it should be done."
- "We don't really **trust** the government."

- "So a **judge says 'Give it up.'** That would be a major concern."
- "For all we know **they already know** who is susceptible... The scientists are already testing."

- "This test here will probably be **entered into a data base.**"
- "Who **controls** the data base?"
- "**The FBI** will have all of this."

- "It like a Big Brother thing. The **corporations are owned by the insurance companies.** That might keep me from getting the test."

Voluntariness

- "If you're exposed to it ... I think it should be mandatory. But if you're not exposed to it I think it should be voluntary."

- "I'd say voluntary because of your civil liberties."

- "After education you have a choice."

- "Pay him some wages to go down and get it done. Giving him time off on top of that. Make him aware that it's really helpful..."

Venue and Sponsorship

Role of Employer

- "LANL should be paying for it."
- "Well then they're gonna have **influence...**"

- "It would be better to have a **group not associated with LANL...**"
- "This testing lab needs to be **totally, totally, totally independent**"
- "If they **receive a paycheck** from the Lab they shouldn't be allowed to do the studies."
- "... complete financial separation..."

- "There's got to be a group that's **not politically involved.**"
- "...away from the Lab Director's office..."
- "It has to be outside... totally independent..."

- "All of a sudden they called me on the PA system. They told me to meet the **paddy wagon to get a drug test** in the parking lot."

Venue and Sponsorship (cont'd)

- "Are they telling you **the truth** when they say it's negative?"

- "I'd like to spread it around ... It probably would be better to get more than one group involved.... So there's not influence on just one company."

- "...the CDC... We have brilliant people, brilliant organizations..."

- "A watchdog group."

- "An environmentalist. Somebody that has dedicated their life to the health and growth of the human race ... Who can't be bought."

- "The companies oughta set up a safety board. And put the workers in charge ... Choose a guy that's a B.A. And have him in charge. That way the workers can say what they feel and how they feel. And the B.A. can get the information they need."

Results

- Knowledge and Beliefs
 - General
 - Heritability or genotoxicity?
 - "Great expectations"
- Benefits and Burdens

- Attitudes on
 - privacy
 - voluntariness
 - venue and sponsorship
 - Family issues
 - Response to results
 - Risk numbers

Family Issues

- "Considering the history I have in my family, this would be just a perfect fit for my family." (father CBD, sibling BeS, spouse exposed)

- "You've got to plan your future and your needs, your relatives, the people you're around. And you've got to take care of your membership."

Response to Results: Who would you tell?

- "You've got to tell your doctor at some point."
- "You could have two or three doctors. Which one gets it?"
- "Employer. Immediate family."
- "Somebody higher up than my immediate supervisor that I'm not gonna be working around that no more. And hope they'd leave it at that."
- "My fellow worker. 'Hey my test came out positive, due. So you've probably got it.'"
- "My spouse." "My family."
- "...[M]y children so they could be tested."
- "My daughter... She's studying to be an environmentalist."
- "My Mom"

Who would you not tell?

- Family: "...worried to death"
- Insurance company
- Employer

Does this genetic test...

...Tell me something I don't know?

No genetic test

Disease prevalence
≈ 5%

Glu69 genetic test

PPV ≈ 14%

Risk Numbers

Rejected the Premise of the Question

- "I'm gonna say it's about 25% of the people I've worked with."
- "I'll give you another that'll probably shock you. It's about 50-50."
- "One percent is too much. If you are in the 1% group, adios."

~ Accepted the Premise of the Question

- "If right now 5% of the people could be susceptible [sic] to it and they did the genetic studies and found out that it's a lot more, it goes up to 15%, double or triple ... That's so important."

"And what's even more important is how the control levels change after they find out the increase."

Arguments **Against**

1. Insufficient **education** to date of workers and families
2. de facto violations of **privacy** in a "company town"; no "accountability"
3. No consensus on **sponsorship and venue**
4. **Insurability**
5. No policies yet on
 - Self-disclosure
 - Prophylactic **removal**
6. "Superman syndrome" > IH protections

ESPANOLA TEAM

