

Survey Instrument: Union Presidents

SURVEY OF WORKPLACE HEALTH AND GENETIC SCREENING AND MONITORING

LABOR UNION VERSION

The Congressional Office of Technology Assessment is conducting a national survey of the opinions and experiences of unions related to the use of genetic screening and monitoring in the workplace. We need your assistance in answering as best you can, some questions about workplace testing and member health in your union.

For the purposes of this survey and the subsequent report, OTA has adopted the following definitions. By genetic monitoring we mean periodically examining members to evaluate modifications of their genetic material via tests such as cytogenetic or direct-DNA tests. **By genetic screening, we mean screening members or potential members for certain inherited characteristics. Screening tests may be biochemical tests or direct-DNA tests.** They can be used to indicate a predisposition to an occupational illness if exposed to a specific environmental agent, or they could be used to detect any inherited characteristic such as Huntington's disease. In contrast to periodic monitoring screening tests are generally performed only one time per characteristic

This is an important study, which has been requested by the Congress of the United States, designed to represent the opinion and experience of leading unions. We need to know how unions view the new technology of genetic screening and monitoring in terms of its current and future applications to the workplace. We also want to know how these technologies are seen in the broader context of more common forms of employee health screening and monitoring in the workplace.

Your responses are very important, regardless of whether your union has had any experience with genetic screening or monitoring. If your union has never explored the technology, the questionnaire will only take ten minutes. If you have some experience with the technology, it may take a little longer to complete the questionnaire. In either case, your experiences and opinions will help to inform congressional opinion about this area.

Please read each question and mark the box(es) that most nearly corresponds to your answer. After each answer continue with the next question unless there is an instruction to skip to a particular question. Please feel free to qualify your answers, if you feel it is necessary. Space has been provided at the end for comments and opinions that you feel are not adequately represented by the survey questions.

You are free to decline to answer any questions that you consider inappropriate. The questionnaire and any identifying information will be destroyed after data entry, so that all responses will be anonymous as well as confidential.

1. Are health examinations required by companies that employ members of your union of all, most, some, few or no members?

a
All

Most

Some

Few

None → **SKIP to Q.3**

4b. Which, if any, of the following types of screening are conducted to identify increased individual susceptibility to workplace risk?

	CHECK ALL THAT APPLY CONDUCTED BY UNION	CONDUCTED BY COMPANY
Medical History.....	1	<input type="checkbox"/>
Non-genetic screening (e.g., lower back X-ray, allergy testing)....	<input type="checkbox"/>	<input type="checkbox"/>
Genetic screening	<input type="checkbox"/>	<input type="checkbox"/>
Genetic Monitoring.	<input type="checkbox"/>	<input type="checkbox"/>
None.	•1	<input type="checkbox"/>

5. Does your union have a formal policy related to the use of genetic tests in the screening of employees or job applicants?

No
 Yes

6. Does your union have a formal policy related to the use of genetic tests in the monitoring of employee health?

Ho
 Yes

7. Has your union ever recommended to a company that it change a workplace practice or exposure level due to the results of:

	YES	NO
Genetic monitoring in establishment(s) where your members work.	• <input type="checkbox"/>	1
Other non-genetic medical monitoring in establishment(s) where your members work	<input type="checkbox"/>	<input type="checkbox"/>
Genetic monitoring in establishments where your union is not represented	• <input type="checkbox"/>	1
Other non-genetic medical monitoring in establishments where your union is not represented	<input type="checkbox"/>	<input type="checkbox"/>
Information published by federal agencies, including NIOSH and OSHA.	<input type="checkbox"/>	<input type="checkbox"/>

8. Have union contract negotiations ever covered the topic of genetic screening and/or genetic monitoring?

No
 Yes

9. Has your union ever filed an employee grievance related to genetic screening or monitoring?

No → SKIP TO Q.10
 Yes

9a. Did that grievance involve employee firing, transfer or something else?

- Firing Transfer Other

10. To the best of your knowledge, has a member of your union applying for a job been rejected, primarily or partly, based on the results of genetic screening tests?

- Yes No → SKIP TO Q.11

10a. When was the most recent time that occurred?

- Within past month.....: 1
Within past year.....
1-2 years ago.....*.....
3 or more years ago.....

10b. What was the condition(s)?

10c. Was alternative employment within the company offered?

- Yes No

11. To the best of your knowledge, has any member of your union been transferred or terminated by a company based on the results of genetic screening or monitoring?

- Yes No → SKIP TO Q.12

ha. When was the most recent time that occurred?

- Within past month.....
Within past year.....
1-2 years ago.....
3 or more years ago.....

11b. What was the condition?

12. Does your union maintain statistical data on the reasons for job terminations?

Yes No → SKIP TO Q.13

12a. Are biochemical and cytogenetic tests used as rejection categories in these data?

Yes No

12b. Are other medical criteria used as rejection categories in these data?

Yes No

13. Would your union consider It acceptable or unacceptable for an employer to conduct a health examination of job applicants In order to:

	ACCEPTABLE	UNACCEPTABLE
Identify job applicants who are physically unfit for employment	<input type="checkbox"/>	<input type="checkbox"/>
Identify job applicants who are emotionally or psychologically unstable : 1		<input type="checkbox"/>
Identify job applicants who are currently using drugs : 1		<input type="checkbox"/>
Identify job appl icants who are at increased risk to workplace hazards	<input type="checkbox"/>	<input type="checkbox"/>
Identify Job appl icants with genetic susceptibility to workplace exposures.... 1		c 1
Identify job appl icants who represent high insurance risks. : 1		<input type="checkbox"/>

14. How do you feel about the following general statements concerning genetic screening and monitoring in the workplace? For each statement, please indicate whether you agree strongly, agree somewhat, disagree somewhat, or disagree strongly.

	AGREE STRONGLY	AGREE SOMEWHAT	DISAGREE SOMEWHAT	DISAGREE STRONGLY
It's fair for employers to use genetic screening to identify individuals whose increased risk of occupational disease poses a threat for greater costs to the employer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The employer should have the option of deciding how to use the information obtained through genetic screening and monitoring.....	<input type="checkbox"/>			<input type="checkbox"/>
The decision to perform genetic screening of Job applicants and employees should be the employer's.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The decision to perform genetic monitoring of employees should be the employer's.....	<input type="checkbox"/>			<input type="checkbox"/>
Government agencies should provide guidelines for genetic screening of job applicants and employees.....	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>
Government agencies should provide guidelines for genetic monitoring of employees.....	<input type="checkbox"/>	<input type="checkbox"/>		
Genetic screening in the workplace represents a potential threat to the rights of employees.....	<input type="checkbox"/>		<input type="checkbox"/>	

15. Would your union consider the use of genetic screening or monitoring of employees or job applicants by employers as generally acceptable or generally unacceptable to:

	GENERALLY ACCEPTABLE	GENERALLY UNACCEPTABLE
Make a clinical diagnosis of a sick member.....	<input type="checkbox"/>	
Establish links between genetic predisposition and workplace hazards.....	<input type="checkbox"/>	<input type="checkbox"/>
Inform members of their increased susceptibility to workplace hazards.....	<input type="checkbox"/>	
Exclude members with increased susceptibility from risk situations.....	<input type="checkbox"/>	<input type="checkbox"/>
Monitor chromosomal changes associated with workplace exposures.....	<input type="checkbox"/>	
Establish evidence of pre-employment health status for liability purposes.....	<input type="checkbox"/>	<input type="checkbox"/>

23. Has your union conducted any of the following tests, either currently or in the past, as part of a voluntary wellness program, at the request of a member, or for diagnosis? (MARK ALL THAT APPLY)

		BIOCHEMICAL GENETIC SCREENING	CYTOGENETIC MONITORING	DIRECT-DNA SCREENING	DIRECT-DNA MONITORING
a. As part of a voluntary wellness program	Currently.....	<input type="checkbox"/>	<input type="checkbox"/>		
	In past 19 years	<input type="checkbox"/>	<input checked="" type="checkbox"/>		
	No.....	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Not sure.....	<input type="checkbox"/>	<input type="checkbox"/>		
b. At the request of the member:	Currently.....	<input checked="" type="checkbox"/>	<input type="checkbox"/>		
	In past 19 years	<input checked="" type="checkbox"/>		<input type="checkbox"/>	
	No.....	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
	Not sure.....	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>
c. For diagnosis:	Currently	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>
	In past 19 years	<input type="checkbox"/>	<input checked="" type="checkbox"/>		<input type="checkbox"/>
	No.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Not sure.....	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

IF YOUR UNION HAS NEVER DONE BIOCHEMICAL GENETIC SCREENING, CYTOGENETIC MONITORING, DIRECT-DNA SCREENING, OR DIRECT-DNA MONITORING, SKIP TO QUESTION 32 ON PAGE 12

IF YOUR UNION HAS DONE CYTOGENETIC MONITORING, DIRECT-DNA SCREENING, OR DIRECT-DNA MONITORING OF MEMBERS, FOR ANY PURPOSE, BUT NOT BIOCHEMICAL GENETIC SCREENING, SKIP TO QUESTION 25 ON PAGE 10

IF YOUR UNION HAS EVER DONE BIOCHEMICAL GENETIC SCREENING OF ANY MEMBER, FOR ANY PURPOSE, PLEASE CONTINUE WITH QUESTION 24

24. Which of the following types of biochemical screening tests are being conducted by your union of any members or potential members? (MARK AU THAT APPLY)

FOR EACH TEST CONDUCTED, MARK WHETHER THE TESTING IS BEING DONE ON A ROUTINE BASIS FOR HEALTH SURVEILLANCE, AS PART OF A VOLUNTARY RESEARCH PROGRAM, AS PART OF FOLLOW-UP DIAGNOSIS, OR AS PART OF A VOLUNTARY WELLNESS PROGRAM, OR ONLY AT THE REQUEST OF A MEMBER

	NOT DONE	ROUTINE HEALTH SURVEILLANCE	VOLUNTARY RESEARCH PROGRAM	FOLLOW-UP DIAGNOSIS	VOLUNTARY WELLNESS PROGRAM	AT MEMBER REQUEST
Sickle cell trait: 1	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		
Glucose-6-phosphate dehydrogenase deficiency (G-6-PO)	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>	
Methemoglobinemia deficiency	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>			<input type="checkbox"/>
alpha-1 def	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>
Alpha and beta thalassemlas.: 1	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>
Aryl hydrocarbon	<input type="checkbox"/>	<input type="checkbox"/>			<input type="checkbox"/>	<input type="checkbox"/>
vs. fast	<input type="checkbox"/>		<input type="checkbox"/>			<input type="checkbox"/>
Allergic respiratory disease	<input type="checkbox"/>	<input type="checkbox"/>			<input type="checkbox"/>	<input type="checkbox"/>
Contact	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>
(HIA)	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>			<input type="checkbox"/>
Bloom	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
.....: 1	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
.....	<input type="checkbox"/>			<input type="checkbox"/>		
.....	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>
Other	<input type="checkbox"/>			<input type="checkbox"/>		

25. Which of the following types of cytogenetic monitoring are being conducted by your union of any members?
(MARK ALL THAT APPLY)

FOR EACH TEST CONDUCTED, MARK WHETHER THE TESTING IS BEING DONE ON A ROUTINE BASIS FOR HEALTH SURVEILLANCE, AS PART OF A VOLUNTARY RESEARCH PROGRAM, AS PART OF FOLLOW-UP DIAGNOSIS, AS PART OF A VOLUNTARY WELLNESS PROGRAM, OR ONLY AT THE REQUEST OF A MEMBER

	NOT DONE	ROUTINE HEALTH SURVEILLANCE	VOLUNTARY RESEARCH PROGRAM	FOLLOW-UP DIAGNOSIS	VOLUNTARY WELLNESS PROGRAM	AT MEMBER REQUEST
Chromosome aberrations : 1				<input type="checkbox"/>	n	<input type="checkbox"/>
Sister chromatid exchanges : 1		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	n	<input type="checkbox"/>
Mutations by assaying the DNA. : 1		<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>	
Mutations by assaying the enzyme/protein... <input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	n	<input type="checkbox"/>
HPRT mutation rate. <input type="checkbox"/>			<input type="checkbox"/>	<input type="checkbox"/>	n	<input type="checkbox"/>
DNA adduct formation. : 1		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other (SPECIFY) _____ <input type="checkbox"/>		<input type="checkbox"/>	1	<input type="checkbox"/>	0	<input type="checkbox"/>

26. To the best of your knowledge, which of the following were important factors in the decision to conduct genetic screening of your members?

	IMPORTANT	NOT IMPORTANT
Cost benefit analysis <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Evidence of a possible association between chemical exposure and illness in animal studies. <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Evidence of a possible association between chemical exposure and illness in epidemiological studies. <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Legal consequence of failure to test <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Union/employee initiative : 1 <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Something else. (PLEASE SPECIFY) <input type="checkbox"/>	<input type="checkbox"/>	1

27. Are all members routinely informed of abnormal (positive) findings, normal (negative) findings, both or neither from genetic screening and monitoring tests?

- Abnormal (positive).
- Normal (negative).
- Both
- Neither

28. Is counseling offered to all members with abnormal (positive) genetic test results by the union or are they referred to *their own* physicians?

Union counseling.....

Referred to own physicians... : 1

29. Does your union employ or contract with a genetic counselor?

Employ

Contract with

Neither

30. Has a member ever been referred for genetic counseling by your union's medical staff as a result of any medical or genetic testing?

Yes

No

31. As a result of a genetic screening or monitoring program has your union ever—?

	YES	NO
Suggested a member seek a job in another company.....	<input type="checkbox"/>	
Suggested a member seek a transfer to a different job in the same company.....	<input type="checkbox"/>	
Recommended company implement engineering control.....	<input type="checkbox"/>	
Recommended company provide personal protection devices.....	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Recommended company implement a research program.....	<input type="checkbox"/>	<input type="checkbox"/>
Recommended company discontinue a product or change materials in a product.....	<input type="checkbox"/>	<input type="checkbox"/>
Some other action (PLEASE SPECIFY).....	<input type="checkbox"/>	<input type="checkbox"/>

32. Is your union currently considering conducting direct-DNA screening of members or potential members for any reason?

Yes No Not Sure

33. Is your union currently considering conducting direct-DNA monitoring of members or potential members for any reason?

Yes No Not Sure

34. Does your union anticipate conducting any biochemical genetic screening, for any reason, in the next five years?

1 Yes **1** No **1** Not Sure

35. Does your union anticipate conducting any cytogenetic monitoring, for any reason, in the next five years?

Yes No Not sure

36. Does your union anticipate conducting any direct-DNA screening, for any reason, in the next five years?

Yes No **1** Not Sure

37. Does your union anticipate conducting any direct-DNA monitoring for any reason, in the next the years?

Yes

no

Not sure

38. Which office/division within the union is/will be responsible for administering genetic tests?

39. Has genetic screening or monitoring ever been done of your union members based on:

	CHECK ALL THAT APPLY	
	CONDUCTED BY UNION	CONDUCTED BY COMPANY
Family History.....	<input type="checkbox"/>	<input type="checkbox"/>
Gender.....	<input type="checkbox"/>	<input type="checkbox"/>
Ethnic/racial background...	<input type="checkbox"/>	<input type="checkbox"/>
Co-factors (e.g. smoking).. 1	<input type="checkbox"/>	<input type="checkbox"/>
Job exposures.....	<input type="checkbox"/>	<input type="checkbox"/>
NO TEST CONDUCTED.....: 1	<input type="checkbox"/>	<input type="checkbox"/>

DEMOGRAPHICS

D1. What are the major industrial classifications (such as chemicals, food, textiles, etc.) of those companies in companies in which your members work?

D2. Approximately how many members does your union have?

D3. What is your job title?

D4. What are your main job responsibilities?

Thank you very much for your cooperation in answering our questions. We would also like to give you an opportunity to give us any other opinions, concerns or suggestions related to genetic testing in the workplace that you feel our questions did not address. These comments may be incorporated in our report to Congress. We would also appreciate your comments on any survey questions that you found confusing or difficult to answer, to help us analyze the results. Please write these comments below.

We have attached a peel-off identification number on the questionnaire. This is the only link between the unions who were sampled and the questionnaires returned. We would prefer that you leave the identification number on the questionnaire when you return it. Our staff will remove the label upon receipt, making the questionnaire completely anonymous. No linkage between unions and questionnaires will be retained. The label from the completed questionnaire will allow us to eliminate your union from those that we have to recontact.

However, if you feel that you cannot complete the questionnaire if there is even temporary identification, then peel off the label before returning the questionnaire. We appreciate your help and we want you to be comfortable with doing the survey.

*PEEL OFF LABEL WITH SAMPLE
IDENTIFICATION NUMBER HERE*

**PLEASE RETURN IN THE POSTAGE PAID RETURN ENVELOPE SENT WITH THE QUESTIONNAIRE.
IF THE RETURN ENVELOPE HAS BEEN LOST, THE RETURN ADDRESS IS:**

**Schulman, Ronca and Bucuvalas, Inc.
444 Park Avenue South
New York New York 10016**

(212) 481-6200 Attn: Dr. Mark Schulman