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 <u>genetic monitoring</u> wc mean periodically examining members to evaluate modifications of their genetic material via tests such as cytogenetic or direct-DNA tests. By <u>genetic screening</u>, wc 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 arc 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 arc seen in the broader context of more common forms of employee health screening and monitoring in the workplace.

Your responses arc 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 rninutes. If you have some experience with the technology, it may take a little longer to complete the question-naire. 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 arc 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.

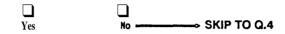
1. Are health examinations required by companies that employ members of your union of all, most, some, few or no members?



| 2. | . Which of the following are normally part of the examination that is given by companies for y | our | union |
|----|------------------------------------------------------------------------------------------------|-----|-------|
| | members? (MARK AU THAT APPLY) | | |

| Personal medical history | Chest X-ray 1 |
|------------------------------------|---------------------------------------|
| family medical history 1 | Pulmonary function test |
| Simple physical examinations 1 | Eye and hearing exam. \ldots \Box |
| Standard blood chemistry tests • 1 | Urinalysis for drug use |
| EKG • | Lower back X-ray 1 |
| | |

3. Are any members of your union exposed to chemicals or ionizing radiation in the workplace setting?



3a. Are those members who are exposed to chemicals or ionizing radiation routinely rotated to avoid prolonged exposure?

| 1 | 1 |
|-----|----|
| Yes | no |
| | |

3b. Does your union conduct any form of medical surveillance of employees whose job may expose them to environmental health risks?

| Yes | No |
|-----|----|

4. Are any members of your union exposed to any known workplace condition where there is a greater risk of negative health outcome, depending upon individual susceptibilities?



4a. Is any form of screening conducted to identify members of your union at increased risk for these jobs?

Yes, by union

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Yes, by company Yes, by union and company

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

| | CHECK ALL 1 Conducted By Union | THAT APPLY CONDUCTED BY COMPANY |
|--------------------------------------------------------------------|--------------------------------------|---------------------------------------|
| Medical History | • 1 | |
| Non-genetic screening (e.g lower back X-ray, allergy testing | _{J)} 🗖 | |
| Genetic screening | 🗅 | |
| Genetic MonitorIng | 🗅 | |
| None | -1 | |

S. Does your union have a formal policy related to the use of genetic tests in the <u>screening</u> of employees or job applicants?

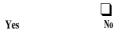
6. Does your union have a formal policy related to the use of genetic tests in the <u>monitoring</u> of employee health?

| Yes | Но |
|-----|----|

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 | | 1 |
| Other non-genetic medical monitoring in establishment(s) where your members work | <u>.</u> | |
| Genetic monitoring in establishments where your union is not represented | Ū | 1 |
| Other non-genetic medical monitoring In establishments where your union is not represented | | |
| Information published by federal agencies, including NIOSH and OSHA | | |

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



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 | L Transfer | Other | |
|-----|---------------------------------------------------------------------------------------------------------------|----------------|------------------|---------------------------------------|
| 10. | Fo the best of your knowledge, hat partly, based on the results of gen | | | for a job been rejected, primarily or |
| | | Yes | No | → SKIP TOQ.11 |
| | 10a. When was the most recent t | time that occ | urred? | |
| | Within past month Within past year 1-2 years ago | | | |
| | 10b. What was the condition(s) | ? | | |
| | 10c. Was alternative employmen | t within the | company offered? | |
| | | Yes | No | |
| 11. | To the best of your knowledge, has based on the results of genetic so | | | ransferred or terminated by a company |
| | [Ye |] es | No | SKIP TO 0.12 |
| | ha. When was the most recent Within past month. Within past year. 1-2 years ago. 3 or more years ago. | | curred? | |

11b. What was the condition?

| - | | n the reasons for job terminations? |
|---------------------|----------------------------|-------------------------------------------|
| | Yes | u ∞ |
| 12a. Are biochemica | l and cytogenetic tests | used as rejection categories in these dat |
| | Yes | No |
| 12b. Are other me | dical criteria used as rej | ection categories in these data? |

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

| ACC Identify job applicants who are physically unfit for employment | | |
|-----------------------------------------------------------------------------|-----|-----|
| Identify job applicants who are emotionally or psychologically unstable | · 1 | |
| Identify job applicants who are currently using drugs | • 1 | |
| Identify job appl icants who are at increased risk to workplace hazards | | |
| Identify Job appl icants with genetic susceptibility to workplace exposures | . 1 | c 1 |
| Identify job appl icants who represent high insurance risks | : 1 | |

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.

| somewnat, or disagree strongly. | AGREE | | DISAGREE | |
|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------|--------------|----------|----------|
| 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 | | Y SOMEWHAT S | | STRONGLY |
| The employer should have the option of deciding how to use the informa obtained through genetic screening and monitoring | ation | | | |
| The decision to perform genetic screening of Job applicants and em ployees should be the employer's | - • 1 | | | |
| The decision to perform genetic monitoring of employees should be the employer's. | ם | | | |
| Government agencies should provide guidelines for genetic screening o job applicants and employees | f 🗖 | | | |
| Government agencies should provide guidelines for genetic monitoring employees. 000000 | of 🗖 | | | |
| Genetic screening in the workplace represents a potential threat to the rights of employees | | | | |
| | | | | |

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

| | GENERALLY ACCEPTABLE | GENERALLY UNACCEPTABLE |
|---------------------------------------------------------------------------|-------------------------|---------------------------|
| Hake a clinical diagnosis of a sick member | | |
| Establish links between genetic predisposition and workplace hazards | | |
| Inform members of their increased susceptibility to workplace hazards | 🗅 | |
| Exclude members with increased susceptibility from risk situations | | |
| Monitor chromosomal changes associated with workplace exposures | 🗖 | |
| Establish evidence of pre-employment health status for liability purposes | | |

16. If an employer becomes aware that an employee has a genetic susceptibility to serious illness if he or she is exposed to substances In the workplace, do you think the employer should exclude that employee from those jobs for which he/she is at increased risk, or do you think the employer should allow the employee to take those jobs, if he/she waives corporate liability?

| Should be excluded | Allowed | to | take | 0 |
|--------------------|---------|----|------|---|
|--------------------|---------|----|------|---|

Yes

The following questions concern biochemical genetic screening and/or cytogenetic monitoring that may have been conducted by your union on one or more members or potential members. By conduct we mean perform, contract for, or arrange for the test as part of a routine or ongoing program.

17. Is your union currently conducting <u>biochemical genetic screening</u> of any members or potential members, for research or any other reason?

No

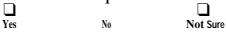
| 18. Has your union conducted any biochemical genetic screening of any members or potential members, for |
|---------------------------------------------------------------------------------------------------------|
| |
| research or any other reason In the past 19 years? |

• 1

Not Sure

| | Yes | No | | Not sure |
|--------------|------------|-------------|------------|----------------------------|
| on currently | conducting | cytogenetic | monitoring | of any members or potentia |

19. Is your union currently conducting cytogenetic monitoring of any members or potential members, for research or any other reason?



20. Has your union conducted any <u>cvtogenetic monitoring</u> of any members or potential members, for research or any other reason in the past 19 years?

| Yes | Но | Not Sure | |
|----------------------------------|----------------|---------------------------------|----|
| rrently conducting <u>direct</u> | -DNA screening | g of any members or potential m | en |
| er reason? | | | |

21. Is your union currently conducting <u>direct-DNA screening</u> of any members or potential members, for research or any other reason?

| Yes | No | Not Sure |
|-----|----|----------|

22. Is your union currently conducting <u>direct-DNA monitoring</u> of any members or potential members, for research or any other reason?

| Yes | No | Not Sure |
|-----|----|----------|

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 | Current ly | 🛛 | | | |
| | In past 19 years | 🗖 | | | |
| | No | •. 1 | | | |
| | Not sure | 🗖 | | | |
| b. At the request of the member: | Currently | 1 | | | |
| | In past 19 years | 1 | | | |
| | No0.00 | : 1 | | | |
| | Not <i>sure.</i> | • ¹ | | | |
| c. For diagnosis: | Currentl y | | | | |
| | In past 19 years | . | 1 | | |
| | No | D | | | |
| | Not sure | •1 | | | |

IF YOUR UNION HAS NEVER DONE BIOCHEMICAL GENETIC SCREENING, CYTOGENETIC MONI-TORING, DIRECT-DNA SCREENING, OR DIRECT-DNA MONITORING, SKIP TO QUESTION 32 0N 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 0N 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 Surveilland | VOLUNTARY RESEARCH CE PROGRAM | FOLLOW-UP DIAGNOSIS | VOLUNTARY Wellness Program | AT MEMBER REQUEST |
|-------------------------------------------------------|----------------------------------|-------------------------------------|------------------------|----------------------------------|-------------------------|
| Sickle cell trait 1 | | | | | |
| Glucose-6-phosphate dehydrogenase Geficiency (G-6-PO) | | | | | |
| Hotherselebin rechement deficiency | | <u> </u> | | | |
| alpha-1 def | | 0 | | | |
| Alpha and beta thalassemlas 1 | | u | | | |
| Aryl hydrocarbon | yı dur | | | | |
| vs. fast 0 | | | | | |
| Allergic respiratory disease | | | | | |
| Contact | | | | | |
| (HIA)• 1 | | | | | |
| Other 🖵 | | | | | |
| Bloom | | | | | |
| • 1 | | | | | |
| | | | | | |
| | | | | | |
| Other 1 | | | | | |

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 | VOLUNTA WELLNESS PROGRAM | RY AT MEMBER REQUEST |
|------------------------------------------|-----------------------------------|----------------------------------|------------------------|--------------------------------|----------------------------|
| Chromosome aberrations 1 | | | | n | |
| Sister chromatid exchanges 1 | | | | n | |
| Mutations by assaying the DNA 1 | | | | | |
| Mutations by assaying the enzyme/protein | | | | n | |
| HPRT mutation rate. | | | | n | |
| DNA adduct formation | | | | | |
| Other (SPECIFY) | | | | | |
| | | 1 | | 0 | |

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

| Cost benefit analysis | | NOT IMPORTANT |
|---------------------------------------------------------------------------------------------------------|----------|---------------|
| Evidence of a possible association between chemical exposure and illness In animal studies | <u> </u> | |
| Evidence of a possible assocciation between chemical exposure and Illness in epidemi ol ogi cal studies | | |
| Legal consequence of failure to test | D | |
| Union/employee initiative | | D 1 |
| Something else. (PLEASE SPECIFY) | | T |

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 (negat | ive) | |
| 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?

| Referred to | Union counseling | | | |
|-------------|------------------|---------------|----------|--|
| | Empl oy | Contract with | Nei ther | |

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 | | |
| Suggested a member seek a transfer to a different job in the same company | | |
| Recommended company implement engineering control | | |
| Recommended company provide $\ensuremath{personal}$ protection devices | | |
| Recommended company implement a research program | | |
| Recommended company discontinue a product or change materials in a product. | | |
| Some other action (PLEASE SPECIFY) | | |

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

| | Yes | No | Not Sure |
|---------------------------------------------------------------------------------------------------------------------------------|-----------------|----------------|----------------------|
| 33. Is your union currently considering conducting <u>direct-DNA monitoring</u> of members or potential members for any reason? | | | |
| | Yes | No | Not Sure |
| 34. Does your union anticipate conducting any <u>biochemical genetic screening</u> , 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 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 an<u>v direct-DNA monitoring</u> 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 TH CONDUCTED BY UNION | |
|--------------------------|---------------------------------------|--|
| Family History | 🗅 | |
| Gender | | |
| Ethnic/racial backgrour | nd | |
| Co-factors (e.g. sinokir | ng) 1 | |
| Job exposures | ם | |
| NO TEST CONDUCTED | | |

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