Appendix C
Survey Materials

March 22, 1982

Dear Mr.

The Committee on Science and Technology of the U.S. House of Representatives has requested this office to carry out a comprehensive study of the policy issues arising from potential occupational genetic testing. The Committee expects the study to provide the Congress with full and fair information on a complex and sensitive topic. A crucial component of our study will be information and advice from leading U.S. corporations. Since your company is a world leader in many areas relevant to the study, we believe it is extremely important for us to benefit from any experience you may have with such testing programs.

The Office of Technology Assessment (OTA) is a nonpartisan congressional agency that assists the Congress in dealing with complex technical issues. OTA is governed by a bipartisan Congressional board composed of six Representatives and six Senators. A council of ten members eminent in science, technology, and education serves in an advisory capacity. This study is also being assisted by an advisory panel of experts in genetics, occupational medicine, law, and policy from industry, labor, and academia. A list of advisory panel members and their affiliations is enclosed.

We have asked the National Opinion Research Center of the University of Chicago (NORC) to assist OTA by collecting and processing data via a questionnaire. The data will be presented to OTA in aggregate form only, and the raw data will be destroyed.

NORC’s brief questionnaire is attached. We believe it will be most helpful if you direct it to your chief executive for health affairs. We respectfully request a response to the questionnaire as soon as possible and are prepared to share the results of the analysis with you when it is completed.

If you have any questions about the study or about OTA, please “feel free to contact me at (202) 224-3695, or Geoffrey M. Karny, OTA project director, at (202) 226-2090. Cynthia Thomas, NORC project director, can be contacted about the survey at (212) 971-8200.

Sincerely,

John H. Gibbons
As one of the leading corporations in this country, your organization has been selected to participate in an important survey we are conducting for the Office of Technology Assessment (OTA) of the United States Congress on the state-of-the-art of genetic and cytogenetic testing programs. The enclosed letter from the OTA describes this study in more detail.

The National Opinion Research Center (NORC) is a not-for-profit academic research corporation affiliated with the University of Chicago. The oldest survey research facility established to do social research in the public interest, NORC has conducted over a thousand studies since its founding in 1941, and has developed careful and systematic methods for ensuring confidentiality. Names are never associated with responses to questions, and data collected are used only for statistical purposes.

It is very important that you complete the enclosed brief questionnaire as soon as possible. Your answers to the questions should include any instance of testing in your corporation, or in any of your subsidiary companies.

To ensure confidentiality, the questionnaire carries no identifying information. Please mail the completed questionnaire in, the prepaid NORC envelope. Then, complete and mail the enclosed prepaid post-card. This will inform us that you have participated in the survey by completing a questionnaire.

If you have any questions about the questionnaire, please feel free to telephone me at (212) 971-8200.

Thank you very much.

Sincerely yours,

Cynthia Thomas
Project Director
WORKPLACE SURVEY

INSTRUCTIONS FOR COMPLETING THE QUESTIONNAIRE

The questions concern biochemical genetic and/or cytogenetic testing that may have been conducted by your company on one or more employees or potential employees. By conduct we mean do, contract for, or arrange for. By biochemical genetic tests we mean tests which screen healthy, asymptomatic individuals for the particular genetic traits listed in question 7, and not standard blood chemistry tests or tests used solely for diagnosis. Cytogenetic tests are intended to detect chromosomal aberrations or sister chromatid exchanges.

Do not sign the questionnaire or record any identifying information on it. Answers should include any instances of testing in your corporation.

Please return the questionnaire to NORC before April 12.

1. Is your company currently conducting biochemical genetic testing of employees or potential employees? Yes No

2. Has your company conducted any biochemical genetic testing of employees or potential employees in the past twelve years? Yes No

3. Does your company anticipate conducting biochemical genetic testing in the next five years? Yes No Possibly

4. Is your company currently conducting cytogenetic testing of employees or potential employees? Yes No

5. Has your company conducted any cytogenetic testing of employees or potential employees in the past twelve years? Yes No

6. Does your company anticipate conducting cytogenetic testing during the next five years? Yes No Possibly

IF YOUR COMPANY NEVER HAS DONE EITHER BIOCHEMICAL GENETIC OR CYTOGENETIC TESTING, SKIP TO QUESTION 18.
### IF BIOCHEMICAL GENETIC TESTING HAS EVER BEEN DONE, PLEASE ANSWER QUESTIONS 7-11. **SKIP TO QUESTION 12.**

7. Has your company tested workers for . . .
   a. any red blood cell and serum disorders, including sickle cell trait, glucose-6-phosphate dehydrogenase deficiency (G-6-PD), methemoglobin reductase deficiency, serum alpha-1-antitrypsin deficiency (SAAT), and beta thalassemias?
   b. any liver detoxification systems, including aryl hydrocarbon hydroxylase inducibility (AH), slow vs. fast acetylation?
   c. any immune system markers, including allergic respiratory disease, contact dermatitis, histocompatibility markers (HLA)?
   d. any heterozygous chromosomal instabilities, including Bloom syndrome, Fanconi syndrome, ataxia-telangiectasia, xeroderma pigmentosum?

   ENTER BELOW NAME OF EACH SPECIFIC CONDITION TESTED FOR (e.g., G-6-PD). Questions 8 & 9 FOR EACH. IF more than 4 CONDITIONS, RECORD ON ADDITIONAL SHEET OF PAPER.

<table>
<thead>
<tr>
<th>ENTER SPECIFIC CONDITION NAME HERE—&gt;</th>
<th>Yes</th>
<th>No</th>
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<td>8. Was testing done . . .</td>
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<td>a) routinely (e.g., yearly) or during regular specified circumstances?</td>
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<td>c) for any other reasons?</td>
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<td>9. Was testing to detect increased risk of disease ever based on employee's . . .</td>
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<td>a) job category?</td>
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<td>b) sex?</td>
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<td>c) ethnic or racial background?</td>
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10. What factors have been considered in decisions to implement any biochemical genetic testing programs?
   A. Cost benefit analysis
   B. Data suggesting a possible association between chemical exposure and illness in animal studies
   C. Data suggesting a possible association between chemical exposure and illness in epidemiologic studies
   D. Legal consequences of failure to test
   E. Union/employee initiative
   F. Something else. What?

11. What criteria were employed in the choice of a specific test?
   A. Predictive value of the test
   B. Sensitivity of the test
   C. Specificity of the test
   D. Scientific consensus
   E. Cost of the test
   F. Something else. What?
12. Has your company tested workers for exposure to chemicals looking for . . .  

<table>
<thead>
<tr>
<th>A. chromosomal aberrations</th>
<th>Yes</th>
<th>No</th>
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<tr>
<td>B. sister chromatid exchanges (SCE)</td>
<td>Yes</td>
<td>No</td>
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<td>C. mutations by assaying the DNA</td>
<td>Yes</td>
<td>No</td>
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<tr>
<td>D. mutations by assaying the enzymes</td>
<td>Yes</td>
<td>No</td>
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<tr>
<td>E. something else? What?</td>
<td>Yes</td>
<td>No</td>
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</table>

Enter below name of each specific condition tested for (e.g., SCE). Answer questions 13 & 14 for each if more than one condition. Record on additional sheet of paper.

13. Was testing done . . .
   a) routinely (e.g., yearly) or during regular specified circumstances?
      [ ] Yes
      [ ] No
   b) for research purposes (e.g., hypothesis testing)?
      [ ] Yes
      [ ] No
   c) for any other reasons?
      [ ] Yes
      [ ] No

14. Was testing to detect increased risk of disease ever based on an employees . . .
   a) job category?
      [ ] Yes
      [ ] No
   b) sex?
      [ ] Yes
      [ ] No
   c) ethnic or racial background?
      [ ] Yes
      [ ] No

15. What factors have been considered in decisions to implement any cytogenetic testing programs?
   A. Cost benefit analysis
   B. Data suggesting a possible association between chemical exposure and illness in animal studies
   C. Data suggesting a possible association between chemical exposure and illness in epidemiologic studies
   D. Legal consequences of failure to test
   E. Union/employee initiative
   F. Something else. What? ____________________________

16. What criteria were employed in the choice of a specific test?
   A. Predictive value of the test
   B. Sensitivity of the test
   C. Specificity of the test
   D. Scientific consensus
   E. Cost of the test
   F. Something else. What? ____________________________
17. Which actions has your company ever taken as a result of biochemical genetic or cytogenetic testing?

A. Informed employee of a potential problem
B. Suggested employee seek job elsewhere
C. Placed an employee or transferred an employee to a different job in the company
D. Implemented engineering controls
E. Recommended personal protection devices
F. Implemented a research program
G. Discontinued a product or changed materials in a product
H. Some other action. What?

18. Has your company ever conducted any testing on whole animals or their cultured cells for... Yes No

A. chromosomal aberrations or sister chromatid exchanges as a result of exposure to workplace chemicals? ☐
B. genetic predisposition to harmful effects from exposure to workplace chemicals?

19. What is the major industrial classification of your company (such as chemicals, food or textiles)?

20. Please use this space for your comments, if any, about these questions.

Thank you for completing this questionnaire. The information you have provided will be held in strict confidence. Data will be made available to Congress in statistical form only.
Dear Mr.

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Sincerely,

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March 23, 1982

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As one of the leading unions in this country, you have been selected to participate in an Important survey we are conducting for the Office of Technology Assessment (OTA) of the United States Congress on the state-of-the-art of genetic and cytogenetic testing programs. The enclosed letter from the OTA describes this study in more detail.

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Please return the questionnaire to NORC before April 12.

1. Is your union currently conducting biochemical genetic testing of members or potential members? Yes No

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3. Does your union anticipate conducting biochemical genetic testing in the next five years? Yes No Possibly

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IF YOUR UNION NEVER HAS DONE EITHER BIOCHEMICAL GENETIC OR CYTOGENETIC TESTING, SKIP TO QUESTION 18.
The Role of Genetic Testing in the Prevention of Occupational Disease

IF BIOCHEMICAL GENETIC TESTING HAS EVER BEEN DONE, PLEASE ANSWER QUESTIONS 7-11. IF NOT, PLEASE SKIP TO Q. 12.

7. Has your union tested members for...
   A. any red blood cell and serum disorders, including sickle cell trait, glucose-6-phosphate dehydrogenase deficiency (G-6-PD), methemoglobin reductase deficiency, serum alpha-1-antitrypsin deficiency (SAT), alpha and beta thalassemias?
   B. any liver detoxification systems including aryl hydrocarbon hydroxylase inducibility (AHH), slow vs fast acetylation?
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   D. any heterozygous chromosomal instabilities including Bloom syndrome, Fanconi syndrome, ataxia-telangiectasia, xeroderma pigmentosum?

ENTER BELOW NAME OF EACH SPECIFIC [CONDITION TESTED FOR (e.g., G-6-PD). ANSWER QUESTIONS 8 & 9 FOR EACH. IF MORE THAN 4 CONDITIONS, RECORD ON ADDITIONAL SHEET OF PAPER.

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10. What factors have been considered in decisions to implement any biochemical genetic testing programs?

   A. Cost benefit analysis
   B. Data suggesting a possible association between chemical exposure and illness in animal studies
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IF CYTOGENETIC TESTING HAS EVER BEEN DONE, PLEASE ANSWER QUESTIONS 12-16. IF NOT, PLEASE SKIP TO Q. 18.

12. Has your union tested members for exposure to chemicals by looking for . . .
   Yes  No
   A. chromosomal aberrations
   B. sister chromatid exchanges (SCE)
   C. mutations by assaying the DNA
   D. mutations by assaying the enzymes
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ENTER BELOW NAME OF EACH SPECIFIC CONDITION TESTED FOR (e.g., SCE). ANSWER QUESTIONS 13 & 14 FOR EACH. IF MORE THAN 4 CONDITIONS, RECORD ON ADDITIONAL SHEET OR PAPER.

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15. What factors have been considered in decisions to implement any cytogenetic testing programs?
   A. Cost benefit analysis
   B. Data suggesting a possible association between chemical exposure and illness in animal studies
   C. Data suggesting a possible association between chemical exposure and illness in epidemiologic studies
   D. Legal consequences of failure to test
   E. Union member initiative
   F. Something else. What?

16. What criteria were employed in the choice of a specific test?
   A. Predictive value of the test
   B. Sensitivity of the test
   C. Specificity of the test
   D. Scientific consensus
   E. Cost of the test
   F. Something else. What?
1. Which actions has your union ever taken as a result of biochemical genetic or cytogenetic testing?

- Informed member of a potential problem
- Suggested member seek job elsewhere
- Suggested member seek transfer to a different job in the corporation
- Recommended corporation implement engineering controls
- Recommended corporation provide personal protection devices

2. Recommended corporation implement a research program

3. Recommended corporation discontinue a product or change materials in a product

4. Implemented our own research program

5. Negotiated items C, D, E or F in a health/safety contract

6. Some other action. What?

8. Has your union ever conducted any testing on whole animals or their cultured cells for . . .

   A. chromosomal aberrations or sister chromatid exchanges as a result of exposure to workplace chemicals?

   B. genetic predisposition to harmful effects from exposure to workplace chemicals?

9. What are the major industrial classifications (such as chemical, food, or textiles) of those companies in the Fortune 500 in which your members work?

10. Please use this space for your comments, if any, about these questions.

Thank you for completing this questionnaire. The information you have provided will be held in strict confidence. Data will be made available to Congress in statistical form only.
OCCUPATIONAL GENETIC TESTING ADVISORY PANEL

Arthur D. Bloom, M. D., Chair
Professor of Pediatrics
Director of Clinical Genetics
and Development
Columbia University

J. Grant Brewen, Ph.D.
Director
Molecular and Applied Genetics
Laboratory
Allied Chemical Corporation

Eula Bingham, Ph.D.
Professor, Environmental Health
University of Cincinnati
Former Director, OSHA

Patricia Buffler, Ph.D.
Associate Dean for Research
and Associate Professor of
Epidemiology
University of Texas
School of Public Health

Ira Cisin, Ph.D.
Director, Social Research Group
George Washington University

Burford W. Culpepper, M.D.
Assistant Director, Medical
Division
E. I. DuPont de Nemours & Company

James D. English
Associate General Counsel
United Steel Workers of America

Neil Holtzman, M.D.
Associate Professor of Pediatrics
Johns Hopkins University

Paul Kotin, M.D.
Consultant
Former Medical Director
Johns-Manville Corporation

Thomas O. McGarity
Professor of Law
University of Texas at Austin

Rafael Moure, Ph.D.
Industrial Hygienist
Oil Chemical & Atomic Workers Union

Robert F. Murray, Jr., M.D.
Professor of Pediatrics and Medicine
Chief, Division of Medical Genetics
Howard University
College of Medicine

Elena Nightingale, M.D., Ph.D.
Senior Program Officer
Institute of Medicine
National Academy of Sciences

Gilbert Omenn, M.D., Ph.D.
Science and Public Policy Fellow
The Brookings Institution

William N. Rem, M.D., M.P.H.
Associate Professor of Medicine
Director, Rocky Mountain Center
for Occupational and Environmental Health
University of Utah

Stuart Schweitzer, Ph.D.
Professor and Director
Program in Health Planning
and Policy Analysis
UCLA School of Public Health

Robert Veatch, Ph.D.
Professor, Medical Ethics
The Kennedy Institute of Ethics
Georgetown University
Respondent Comments About Survey

Respondents were asked to comment about any aspect of the survey or questionnaire in a space provided on the questionnaire and one the postcard. The following list comprises the totality of comments received from the respondents. They have been grouped by status of tester: Current Tester, past Tester, Future Testers with prior testing experience, and No Testing (Past, Present, Future). Information contained at the end of a quote is descriptive information about the respondent provided by the contractor. In cases where a number of appears, it is the Standard Industrial Classification (SIC) Code as given by the respondent. The quotes are printed as written by respondent. No editing has been done.

Comments by present testers

"Answers should not be taken to imply any large scale program or problem. Medical/Ind Hygiene depts have done 'common sense' preventive sampling and testing to reassure employees in specific small areas of company where even low level risk might occur."
- presently biochemical genetic testing and past biochemical genetic testing

"We do a chemical profile (blood test) that tests 20 different factors (sic) in the blood and CBC as a matter of course for pre-placement and annual physical."
- presently biochemical genetic testing and past biochemical genetic testing

"Cytogenetic testing is one aspect of continuing health evaluations on personnel engaged in "hands on" maintenance work in 500KV electric transmission lines."
- presently cytogenetic testing and past cytogenetic testing

Comments by past testers

"Sickle cell trait testing was offered as a service to employees for a brief period at the request of the state health department. It was never used as a screening procedure in relation to the job."
- past biochemical genetic testing
"Only testing has been for sickle trait or mediterranean anemia trait in a few people of child bearing age as part of preventive medical program not consistently".

-past biochemical genetic testing

Comments by companies that anticipate future testing, but have not conducted any testing to date:

"Company supports research activities relevant to No. 18 through trade associations and C11T."

"Such tests as described in 18A are run on materials and products routinely as part of an overall safety assessment."

"Some essential questions have been omitted--namely,
1. are materials being used with chromosomal and/or genetic harmful effects?
2. is there clinical evidence or even suspicion to justify performing such tests? (in a given workplace)
3. are tests results indicators (valid and reliable) of actual or potential health risks to employees?"

"18A, "Chromosomal aberrations" may be included in a mutagenic screen on chemicals or as a followup to mutagenic testing."

"It is conceivable we may wish to initiate a limited project of cytogenetic or biochemical genetic testing in employees "exposed" to nuclear radiation in next 5-10 years. Our stringent monitoring controls on radiation exposure may not result in this requirement. However, it is just a possibility."

"What may be done (#3 and #6) will depend upon demonstration that indicated procedures have practical utility."

FROM A UNION QUESTIONNAIRE: "(NAME DELECTED BY NORC) Plant may have been cytogenetic testing by company for which they worked benzene (sic)"

Comments from companies not now, previously, or in the future planning to test.

" --- Inc. is a multifacility manufacturing co. that is not involved in genetic testing." (540, aircraft)

"We do not perform health testing for the specific purpose of detecting genetic or cytogenetic health effects of occupational exposure to chemicals. We have not conducted this type of health testing since we have not identified chemicals to which our employees are exposed that could potentially cause these genetic health problems." (563, electric utility)

"I really wonder if the value of this project will compare favorably with the cost of it - our federal budget deficit is large and we have operated in the red for decades - this looks like the sort of expenditure the USA could get along without!" (547, cement and construction materials)
“Not needed. Virtually no chemical exposure. Operations are light assembly of prefinished parts of materials”. (612, recreational vehicles)

“Totally out of context with the nature of our business." (613, electronic equipment)

“Does not seem relative to our business”. (616, gas and oil production)

“The need or cause for such testing has never been revealed”. (617, cement)

“Our company presently has done noise level testing at all facilities and “Blood-Lead Chemistry” and “Chest X-ray” testing of all employees working in painting rooms on an annual basis”. (618, Hand tools)

“Privacy of individual employees should not be imposed upon unless there is a clear indication from Public Health authorities that program is warranted and public is informed in a manner that would educate employees on the need for it.” (619, books and journals)

“We have no information that any products we produce require any such testing”. (620, refractories and building materials)

“Company maintains minimal risk environments [through] selective and controlled use of chemical and physical agents in conjunction with continuing industrial hygiene appraisals (622, cross linked plastics)

“Ref. Question #18: The American Petroleum Institute acting on behalf of the industry, is engaged in a major, on-going program of animal testing. Generic petroleum products are employed in this toxicology testing program which includes genetic considerations.” (286, chemicals)

“We are computer and word processing system manufacturers and are not involved in chemical or genetic work.” (292)

“Thank you for sending questionnaire. However, it does not seem relevant to our business or to our future plans.” (219; flat glass, fluid system components, plastic products)

FROM A UNION QUESTIONNAIRE: “Union never conducted tests. Company screening often by union demand has been limited to clinical tests and biological monitoring, no cytogenetic or biochemical genetic tests”. (103, union)

“We have conducted and continue to conduct chemical exposure testing on whole animals and their cultured cells for chromosomal aberrations and sister chromatid exchanges. This is sometimes done as one part of our toxicological evaluations conducted to enable the proper planning and management which assures safe handling and usage of intermediate and product materials.” (453, petroleum products and petrochemicals)

“We have used these tests as screening procedures in animals. We do not find them sufficiently validated for use on our employees, or prospective employees.” (478, petrochemicals)
“In our opinion none of our Industrial operations are associated with environmental hazards which indicate any employee health benefit from either biochemical genetic or cytogenetic testing.” (479, mining, smelting)

“We believe cytogenetic (sic) testing methodology to screen human populations requires further standardization and validation before we would consider using it in our employee population. As a general principle, we are reluctant to utilize a test on employees unless we can explain the result and course of action required. Question 7C was confusing. It was not clear to us what measurements are envisioned in the category of allergic respiratory disease or contact dermatitis.” (366, petroleum)

“Due to the great diversity of operations of this corporation, this questionnaire is not applicable.” (371, no industrial code given)

“We do not engage in any form of biochemical genetic testing or cytogenetic testing. We are primarily a metal forming industry.” (375)

“I have no questions about the above. As a physician who has been in full time occupational practice for 33 years I was amazed to read in the lay press that some union officials were alleging widespread use or plans for use of genetic testing by industry.” (385, chemicals)

“To date we have not had the exposure, and therefore have not seen the need to do these tests.” (305, Food)

“Attention John Gibbons: How can your organization afford Federal Express service from zip code 10001 to 10591 – 20 miles to the North of Manhattan. Signed, A Hard Working Taxpayer” (201, Food processing)

“Our employees are incidentally exposed to degreasers, solvents and non-lead based paints. We look to NIOSH to define areas where biochemical and other testing is prudent. We would discontinue use of any product which would exhibit qualities that would make such testing prudent however we would perform the testing of any of our employees so exposed.” (207, fabricated metal products)

“This questionnaire is another example of wasting Federal tax monies. I would hope that Congress has more important business to conduct than the above questionnaire. Also there must be a more economic way to mail it than Federal Express overnight letter at $9.50.” (231, Lumber and Paper mfg.)

“Biochemical genetic testing: If any thing should be done, it would be accomplished post-natally since appropriate family history would be available. Cytogenetic testing: would be appropriate in areas of exposure to potential chromosomal damaging agents (radation, chemicals, etc.)” (403, manufacturing and resale electricity)

“Is any industry doing this testing?” (118, Food)

“We have reviewed the current data on cytogenetic testing both in animals and in man and feel that these techniques are not yet applicable to standard medical surveillance of workers. It is recognized that the techniques may have potential value in risk assessment, and we hope that continued research
work will better define that applicability. We feel strongly that current capabilities in the field do not allow the widespread use of these techniques at the present time.” (121, manufacture of medical products for the health care industry, including both devices and drugs)

"..." Inc. was selected to participate in a survey conducted by NORC for the Office of Technology Assessment (OTA) of the U.S. Congress on the state of the art of genetic and cytogenetic testing programs. By error, we received a copy of the questionnaire to be completed by a Union as well as a copy to be completed by a corporation.

I was concerned to note that the questionnaires were different in that questions no. 19 and 20 appearing on the union version of the form were absent from the corporation version. I am hopeful that any information you received from the union on these two questions will be deleted from the report to Congress since the data is obviously biased.

Many corporations have decided not to implement genetic and cytogenetic programs since the correlation of results of such testing with frank clinical diseases has not been demonstrated. This lack of predictability can lead to incorrect conclusions on the part of environmentalists and governmental agencies in assessing the risk of certain chemicals and substances. does concur with the scientific literature which indicates that the proportion of occupational diseases attributable to genetic predisposition ranges from 10 to 20 per cent with diseases attributable to chromosomal aberrations ranging 1 to 5 per cent.

If you have any additional questions, please let me know."