

Mercury Public Health Surveillance in Colorado: Phase I and Phase II

Developed by:
The Mercury Surveillance Program
Disease Control and Environmental
Epidemiology (DCEED)

**Colorado Department of Public
Health and Environment (CDPHE)**

September 2008

Table of Contents

Executive Summary	3
Contact Information for Team members:.....	4
Background	5
Purpose	6
Implementation.....	6
Goals.....	7
Privacy and Confidentiality	7
Subject Population	7
Participating Laboratories and Reporting Mechanism	8
Data Management.....	8
Reportable Case Definition	9
Reportable Case Prioritization: Action Thresholds	9
Protocol for exposure investigation	9
Interventions to Prevent Mercury Overexposures	11
Outcome Measures	12
Conclusion	12
Appendices	14
Appendix A. Reporting Rule	14
Appendix B. Letter.....	22
Appendix C. Adult Telephone Questionnaire	23
Appendix D. Child Telephone Questionnaire	32
Appendix E. Toxfacts about Mercury.....	37

Executive Summary

Mercury is a naturally occurring, highly toxic, persistent metal. Mercury exposure is ubiquitous with humans primarily accumulating mercury through certain occupational exposures and fish consumption. Colorado requires clinical laboratories to report all cases of elevated levels of mercury in blood and urine. However, public health surveillance for mercury exposures has not been possible to date.

The Mercury Surveillance Program of the Colorado Department of Public Health and Environment (CDPHE) is initiating a mercury surveillance program for the first time in Colorado; this program will allow the mercury surveillance program team to analyze the reported data, to perform further follow-up investigation, and provide necessary information to affected individuals and health care professionals with the objective of reducing the incidence of elevated levels of mercury among Colorado residents.

The program will develop surveillance procedures, an electronic data recording system, will evaluate the efficacy of the laboratory reporting mechanism, and will conduct the follow-up investigations. The results may demonstrate the necessity to improve data reporting, collection and follow-up practices, and for the creation of a more established program for the surveillance and reduction of mercury exposure among Colorado residents.

Contact Information for Team members:

Raj Goyal, Ph.D
Program Manger/Toxicologist
Raj.Goyal@state.co.us

Shannon Rossiter, MPH
Epidemiologist
Shannon.Rossiter@state.co.us

Tom Simmons
Environmental Health Scientist
Tom.Simmons@state.co.us

Background

Mercury is a naturally occurring, highly toxic, and persistent metal that is released to the environment by natural phenomenon, such as volcanoes, and human activities like the burning of fossil fuels and mining. Once released, mercury is distributed throughout the environment making mercury exposure ubiquitous and all people have at least some amount of mercury in their body. Mercury can accumulate in the body and has unique ability to cause delayed neurological effects with neurodevelopmental effects being the most sensitive and well-documented effects on humans. Published research suggests that health impacts of mercury can also include cardiovascular problems, and impairment of immune and reproductive systems. Exposure to high levels of mercury can permanently damage the brain, the kidney, or the developing fetus. Children exposed prenatally to low levels of mercury are at increased risk of poor performance on neurobehavioral tests. EPA has determined that children born to women with blood mercury concentration of 5.8 µg/L (ppb) are at some increased risk of adverse health effects.

Humans are primarily exposed to mercury through fish consumption and certain occupational exposures. Methylmercury contamination in fish is so pervasive that fish consumption advisories have been issued by federal and state agencies. Recently, the Environmental Protection Agency (EPA) and the Food and Drug Administration (FDA) issued a joint consumer advisory for women who may become pregnant, women who are pregnant, nursing mothers, and young children. At present, Colorado has issued fish advisories at 14 out of 60 water bodies tested.

Elevated levels of mercury in the body is a reportable condition in the State of Colorado as described in the State Board of Health "Regulations Pertaining to the Detection, Monitoring, and Investigation of Environmental and Chronic Diseases" (6 CCR 1009-7). These regulations require that all laboratories report within 30 days of the test, all blood and urine tests where mercury levels exceed 0.5 µg/dL (or 5 µg/L) for blood and 20 µg/L for urine (See Appendix A). Beyond these requirements, every identified case of overexposure presents the opportunity for preventing further harm not only to the individual but also to others. For example, if one household member is exposed, others in the household or community might also be exposed. However, until very recently, the necessary follow-up exposure investigations and health education activities have not been possible due to limited resources.

Furthermore, objective 8-25e of *Healthy People 2010* relates to reducing the body burden of mercury in the population, as measured by blood and urine. The mercury surveillance program team plans to accomplish this objective by building state capacity to conduct mercury surveillance to identify and target public health

activities with the intent of reducing mercury exposures and the related health impacts to Colorado residents.

Purpose

This mercury surveillance program was established by DCEED to improve the tracking, prevention, and mitigation of human health impacts of environmental and occupational exposures to mercury. Like other public health surveillance systems, this system is built on a reporting requirement that includes the collection of sufficient information about tested individuals and for their health care providers to conduct follow-up to identify the source of exposure. Subsequent public health interventions to mitigate or prevent over-exposures may then be initiated, as appropriate. This surveillance may include an increase in public awareness of environmental health issues through education as a cornerstone of a broad prevention effort.

Implementation

This project will be implemented in two phases:

- **Phase I** – This initial period is designed to allow the mercury surveillance program team to “ramp up” surveillance activities. The focus during this initial 6-8 months is on establishing the procedures used to monitor and track affected persons, for example:
 - Procedures used to identify persons for follow-up based on clinical laboratory report.
 - Procedures used to contact health care providers to obtain phone numbers and addresses for persons selected for follow-up.
 - Development of working relationship with the laboratories submitting clinical reports, and the health care providers who often order blood/urine mercury tests.
 - Development of the necessary data management systems.
 - Conduct follow-up with as many persons as possible, subject to resource availability.
 - Analysis of preliminary data.

- **Phase II** - Phase II will begin with a review of Phase I activities. Phase II continues the monitoring and tracking activities begun during Phase I, and the mercury surveillance program team will also focus their efforts on:
 - Completing follow-up questionnaires and exposure investigations on as many selected persons as possible.
 - Translating survey forms and cover letters into Spanish.

- Minimizing the time between laboratory report and follow-up to improve response rates
- Developing an electronic reporting system.
- Developing and recommending interventions for exposure mitigation.
- Creating health education materials.
- Identifying potential occupational (or other) cohorts.
- Identifying common risk factors.
- Interpreting and analyzing data.
- Preparing Annual Reports.
- Improving reporting by Labs/physicians.
- Educating physicians about ordering both urine and blood tests, if possible.

Goals

The goals of this project for Phase I and II are:

Phase I:

- To demonstrate that laboratory based reporting of blood mercury levels can be effectively used to contact individuals with elevated blood levels of mercury.

Phase II:

- To identify potential sources and exposure pathways of mercury exposure
- To identify and conduct public health interventions that might reduce mercury exposures and their potential health impacts in Colorado residents.

Privacy and Confidentiality

All information obtained from case reports will be used for public health surveillance and prevention purposes only. Specific personal identifiers obtained by the mercury surveillance program team will not be shared with any other group or for any other purposes without written permission by the individual. CRS 25-1-122(4)(b) states that release may be made of medical and epidemiological information to the extent necessary for the treatment, control, investigation, and prevention of diseases and conditions dangerous to the public health; except that every effort shall be made to limit disclosure of personal identifying information to the minimal amount necessary to accomplish the public health purpose.

Subject Population

The subject population includes all Colorado residents who received a blood and/or urine test for mercury from their health care provider. Based on reports

received in the first half of 2008, it is estimated that the mercury surveillance program will receive laboratory data on approximately 450-500 individuals annually; approximately 25% of these reports will include individuals with elevated blood and/or urine levels of mercury.

Data from laboratory reports received by the mercury surveillance program in the first six months of 2008 is summarized below:

Total reports	Gender		Age		Blood Mercury Level (ppb) (µg /L)	
240	F	107 (44.6%)	LE 18	7 (2.9%)	< 5	179 (74.6%)
	M	132 (55%)	19 – 45	82 (34.2%)	5 – 9	34 (14.2%)
	Unk	1 (<1%)	46+	150 (62.5%)	10 – 14	12 (5%)
			Unk	1 (<1%)	15+	15 (6.3%)

Participating Laboratories and Reporting Mechanism

Analytical laboratories in Colorado are required to submit elevated blood and urine mercury data as described above. It is assumed that a large proportion of reportable mercury data is currently being submitted. However, the current level of participation by labs handling mercury tests of Colorado residents is unknown and cannot be defined at this time. Major participating laboratories include Quest Diagnostics, Lab Corp, and Specialty Labs.

The labs currently report their data via a paper-based system. Data elements reported include personal identifiers (name and birth date), ordering health care provider contact information, and clinical information (date of test, date of report, clinical test used, and test result). No information is provided about the race or ethnicity of the patient. Furthermore, the majority of reports do not contain any contact information for the patient. Reports are submitted to the mercury surveillance program at a minimum of once per week. The data reported in the first half of 2008 consists entirely of blood mercury. Urine mercury data has been historically reported as well, although in much smaller numbers. The two matrices are not comparable and will be analyzed independently.

Data Management

Laboratory reports are compiled into a central spreadsheet and the data is cleaned to delete duplicate entries. Every month, the data are sorted by date of birth, gender, and clinical result. The data are maintained in compliance with CDPHE policies for the privacy and security of confidential information and protected health information. The central spreadsheet is stored on a network

drive, but access is limited to the project team by a strong password. Paper copies of the laboratory reports, patient contact information, and patient interviews are stored in a locked cabinet in the DCEED. Additionally, DCEED is located behind a locked door with a key card access. The information will be retained for one year. After that, electronic data will be stored on a network drive, with a new password, and all hard copy data will be destroyed. None of the information collected for this pilot project will be used for any other purpose.

Reportable Case Definition

In accordance with the State Board of Health regulation (Appendix A), a reportable case of mercury overexposure is defined as an individual with blood mercury level $> 0.5 \mu\text{g/dL}$ (or $5 \mu\text{g/L}$) and/or urine mercury level $> 20 \mu\text{g/L}$. It should be noted that this case definition is not sufficient for establishing a medical diagnosis. Clinical manifestations of mercury exposure vary based on individual factors (e.g., life style, genetic make up, sex, age, health status), route of exposure, dose, and duration of exposure.

Reportable Case Prioritization: Action Thresholds

Ideally, the goal of the program is to survey each reportable case that is received. Due to the limited mercury surveillance program resources and the anticipated high number of individuals requiring follow-up, contacting each reportable case may not be possible. In this case, the mercury surveillance program has set the following priority for action thresholds for completing the follow-up questionnaire and exposure investigations. These action thresholds are listed in order of priority by which they should be completed:

- All children (less than 18 yrs of age) with blood mercury test result $\geq 5 \mu\text{g/L}$.
- All women of childbearing age (16-45 yrs.) with blood mercury test result $\geq 5 \mu\text{g/L}$.
- All adult male with blood mercury test result $>15 \mu\text{g/L}$ and/or urine mercury test results $>20 \mu\text{g/L}$ (action levels established by American Conference of Industrial Hygienists).
- Every 5th adult with blood mercury test result $\geq 5 \mu\text{g/L}$.

Protocol for exposure investigation

- **Step 1** - Cases are selected based on the case definition and cases are prioritized (if necessary) based on the action thresholds described above.

- The health care provider listed on the laboratory report is contacted by telephone and asked to provide the following information for the patient: contact and demographics such as race.
- Contact information for the patient is entered in the central spreadsheet.
- If a health care provider is determined to be non-responsive after 5 attempts to obtain patient contact information, this individual (the patient) will be removed from any subsequent follow-up and investigation protocols and will be determined to be lost to follow-up.
- **Step 2** – After patient contact information is obtained from the appropriate health care providers, individuals are sent a letter from the mercury surveillance program team (See Appendix B). The purpose of the letter is to introduce the mercury surveillance program team, describe our interest and involvement in mercury surveillance in Colorado, explain how we obtained their contact information, and detail why we want to have them complete the follow-up questionnaire. The complete follow-up questionnaire will be sent along with the letter in order to familiarize individuals with the questions that will be asked, inform them of their rights regardless if they choose to complete the follow-up or refuse, and to promote better completion of telephone interviews (See Appendices C and D).
 - For children, the letter is sent to a parent or guardian.
 - Recipients of the letter are offered 3 options:
 - Complete the follow-up questionnaire on the paper form and return it to the mercury surveillance program.
 - Schedule a time to complete the follow up questionnaire by phone with a member of the mercury surveillance program team.
 - Do nothing. A member of the mercury surveillance program team will contact this individual to complete the follow-up questionnaire over the phone. The mercury surveillance program will initiate this follow up approximately 2 weeks after the letter was mailed.
 - Information collected during the interview includes potential sources of environmental or occupational exposures.

- General information is provided to the case (individual or family) about limiting potential mercury exposures.
- Exposures are also evaluated to determine if additional public health or occupational health and safety measures are warranted to prevent or reduce exposure to others.
- **Step 3** - Data collected via the questionnaires are entered into a separate spreadsheet. The hard copies of the interview data are also stored in a locked cabinet.
- **Step 4** - QA/QC. Every 6 months, approximately 10% of the records are selected for QA/QC and the electronic file is compared to the hard copy record.
 - Errors are noted and corrected for individual patients.
 - Common errors are noted and discussed among the mercury surveillance program team and appropriate modifications to procedures/practices are made.
- If a case selected for follow-up and investigation is determined to be non-responsive after 3 attempts to schedule or complete an interview via telephone, this individual will be removed from any subsequent follow-up and investigation protocols and is determined to be lost to follow-up.
- Any case that cannot be contacted within 3 months of its laboratory test date is removed from the standard follow-up and investigation protocols and is determined to be lost to follow-up.

Interventions to Prevent Mercury Overexposures

The mercury surveillance program interventions to prevent mercury over-exposures may include:

- Conducting follow-up interviews with exposed individuals, physicians, and employers.
- Providing technical assistance to individuals and physicians.
- Providing recommendation for follow-up blood and/or urine tests after reduction in exposure sources.
- Providing referrals to NIOSH and OSHA for occupational exposures.
- Developing and disseminating educational materials.

Outcome Measures

We expect that the Mercury Surveillance Project to provide many opportunities and many challenges. For example, mercury registry was established over two decades ago but no systematic tracking was conducted. The mercury surveillance program is initiating mercury surveillance for the first time in Colorado. Therefore, the response rate of PCPs and affected individuals is unknown. As such, we expect the outcomes measured in Phase I to inform our protocols and procedures as we initiate Phase II. However, once Phase II is underway, our outcome measure will shift focus and become more results oriented.

For example, in Phase I we will measure:

- The number of individuals contacted within one month of receiving their blood test.
- The number of PCPs and/or individuals that responded to our surveillance efforts.

For example, in Phase II we will measure:

- The number of different potential exposure sources and pathways identified for the high blood mercury levels among Colorado residents.
- The number of interventions that result in reduced exposure, as measured by reduction in blood and/or urine mercury levels, based on follow-up testing by the PCP.

Conclusion

The new surveillance project aims to improve the tracking of mercury exposure and thus enable a reduction in exposure to mercury among Colorado residents. The project will evaluate the efficacy of the current reporting mechanism and the voluntary participation of individuals in follow-up investigations in reducing elevated mercury levels among Colorado residents. The new surveillance project will provide information to affected individuals and their families about the potential sources for their mercury exposure. We will analyze the data collected for environmental, occupational, and acute poisoning events affecting Colorado residents. The data will be used to conduct interventions to reduce exposures and potential adverse health effects to both the individuals with the elevated mercury levels, as well as others who because of similar circumstances, face similar risks.

Appendices

<http://www.cdphe.state.co.us/regulations/diseasecontrol/100907environmentalandchronicdisease.pdf>

Appendix A. Reporting Rule



Colorado Department
of Public Health
and Environment

**DEPARTMENT OF PUBLIC HEALTH AND ENVIRONMENT
Disease Control and Environmental Epidemiology Division
6 CCR 1009-7**

**STATE BOARD OF HEALTH
REGULATIONS PERTAINING TO THE DETECTION, MONITORING AND
INVESTIGATION OF ENVIRONMENTAL AND CHRONIC DISEASES**

**Last amended February 15, 2006, effective April 30, 2006
(Regulation 1, List A)**

**STATE OF COLORADO
RULES AND REGULATIONS
PERTAINING TO THE DETECTION, MONITORING, AND INVESTIGATION
OF ENVIRONMENTAL AND CHRONIC DISEASES**

Regulation 1. Reportable Diseases

For the purpose of these regulations, the diseases named in the lists below and any epidemic of environmental or chronic disease are declared to be dangerous to the public health and shall be reportable in accordance with the provisions of these regulations.

Reportable outbreaks or epidemics of environmental or chronic diseases include those which may be a risk to the public and which may affect large numbers or specific groups of persons or be outbreaks caused by a chemical or radioactive terrorist agent or incident or be a newly recognized entity. Such outbreaks may include, but are not limited to, those related to environmental contamination by any hazardous chemical, radiological material, or biologic substance.

The occurrence of a single case of any unusual disease or manifestation of illness which the health care provider determines or suspects may be caused by or related to a chemical or radioactive terrorist agent or incident must be reported immediately by telephone to the state or local health department by the health care provider and the hospital, emergency department, clinic, health care center, and laboratory in which the person is examined, tested, and/or treated. The same immediate reporting is required for any unusual cluster of illnesses that may be caused by or related to a chemical or radioactive terrorist agent or incident. Chemical terrorist agents include, but are not limited to, Sarin (GB), VX (V agent), and HD (distilled mustard).

List A. Environmental and Chronic Diseases Reportable by Physicians or Other Health Care Providers

Diagnosis (Confirmed or Suspected)	Reportable Within:
Fetal Alcohol Syndrome (Age less than or equal to ten years)	30 days
Muscular Dystrophies	120 days

List B. Environmental and Chronic Diseases Reportable by Hospitals and Other Health Care Facilities

Diagnosis (Confirmed or Suspected)	Reportable Within:
Spinal cord injuries	120 days
Birth defects, developmental disabilities, and medical risk factors for developmental delay in Colorado residents diagnosed prenatally, at birth, or through the third birthday*; with the exception of muscular dystrophies, which shall be reported without age limit	120 days
Head injuries requiring admission to hospitals or resulting in death	120 days
Autism Spectrum Disorders (ASD) (Age less than or equal to ten years) (Including Autistic Disorder, Asperger's Syndrome, and Pervasive Developmental Disorder-Not Otherwise Specified)	30 days**

* Appendix A is an inclusive list of conditions that must be reported.

** Seven-county Metro Denver Area (Adams, Arapahoe, Boulder, Broomfield, Denver, Douglas, Jefferson).

List C. Environmental and Chronic Diseases Reportable by Laboratories

All of the findings below are to be reported within 30 days.

- Blood lead level: >25 µg/dL if age >18 years.
Report all blood lead levels if age ≤ 18 years and report levels ≥10 µg/dL within one week of analysis.
- Blood mercury >0.5 µg/dL
- Urine mercury >20 µg/L
- Chromosomal abnormalities and neural tube defects diagnosed by prenatal testing or by genetic testing in Colorado residents through the third birthday (*reportable within 90 days*)

Physicians, health care providers, and clinics performing blood lead level testing in an office or outpatient setting are required to report results the same as the requirement above for laboratories.

Regulation 2. Manner of Reporting and Information To Be Submitted.

The diseases in the lists in Regulation 1 shall be reported to the Department of Health within the specified time frame after the diagnosis is made by the physician, health care provider, or confirmed in a laboratory.

The information to be submitted shall consist of the diagnosis; the patient's name, age, sex, race/ethnicity, and address; the name and address of responsible physician; the employer (for reportable work-related conditions); and such other information as is needed by the Department to locate the patient for follow-up. With regard to birth defects, developmental disabilities, chromosomal abnormalities, and neural tube defects reported pursuant to regulation 1, the department shall collect no additional information about pregnancy outcome other than what is required for the vital record form. When hospitals and laboratories transmit disease reports electronically using systems and protocols developed by the department that ensure protection of confidentiality, such reporting is acceptable and is considered good faith reporting.

Laboratory findings in List C of regulation 1 shall be reported by all laboratories which maintain an office or collection facility in Colorado or which arrange for collection of specimens in Colorado. Results must be reported by the laboratory which performs the test, but an in-state laboratory which sends specimens to an out of state referral laboratory is also responsible for reporting the results.

In addition to physicians, health facilities, and laboratories, any person having knowledge of a reportable disease, outbreak, or epidemic, such as coroners, persons in charge of schools (including school nursing staff), or persons or employees having knowledge of exposure of large numbers or specific groups of persons to a known or suspected public health hazard shall report such disease, outbreak, or epidemic.

The Department shall develop systems and forms for reporting for physicians, other health care providers, hospitals, and laboratories. For birth defects and developmental disabilities, hospitalized head injuries, and spinal cord injuries, hospital reporting shall be through a central computerized data system operated by or for the department.

Reports on hospitalized patients may be made part of a report by the hospital as a whole.

Regulation 3. Procedures for the Investigation of Environmental and Chronic Diseases

The State or local health department shall employ reasonable investigative techniques as part of systematic surveillance for environmental and chronic diseases. Reports of diseases related to exposure to a hazardous substance or agent in one environmental setting may lead the state or local health department to investigate whether or not the public health is endangered either in the same setting or in other settings physically removed but environmentally similar to that of the reported case. Investigations shall be considered official duties of the health department or health agency and shall be pertinent, relevant and only as intrusive as necessary. Such investigative techniques include but are not limited to:

- (a) review by authorized personnel of pertinent, relevant medical records necessary to identify and characterize the index case and other cases in a region, community, or workplace; such review of records may occur without patient consent and shall be conducted at reasonable times and with such notice as is reasonable under the circumstances;
- (b) review of Workers' Compensation claims;
- (c) review of toxic tort or product liability claims filed with state or federal courts within the state;
- (d) medical examination and testing of persons with the explicit consent of such persons;
- (e) obtaining from public or private businesses or institutions lists of persons with a similar or common potential exposure to the hazardous substance or agent as a reported case; such exposure may be current or have occurred in the past;
- (f) performing follow-up interview(s) with a reported case or persons knowledgeable about the case to collect pertinent and relevant information about the cause and/or risk factors associated with the reportable environmental or chronic disease;
- (g) interviewing or administering questionnaire surveys confidentially to any resident of a community or any agent, owner, operator, employer, or employee of a public or private business or institution, that is either

epidemiologically associated with a reported case or has had a similar hazardous environmental exposure as a reported case;

- (h) collecting environmental samples of substances or measurements of physical agents;
- (i) taking photographs related to the purpose of the investigation; if the photographs are taken in a business, the employer shall have the opportunity to review the photographs taken or obtained for the purpose of identifying those which contain or might reveal a trade secret;
- (j) entering a place of employment for the purpose of conducting investigations of those processes, conditions, structures, machines, apparatus, devices, equipment, records, and materials within the place of employment which are relevant, pertinent, and necessary to the investigation; such investigations shall be conducted during regular working hours or at other reasonable times and with such notice as is reasonable under the circumstances.

Regulation 4. Information Sharing

Whenever a local health department or health agency learns of a case of a reportable disease in Regulation 1 or an environmental exposure potentially threatening the public health, it shall notify the State Department of Health in a timely manner, usually within the timeframe for reporting in Regulation 1.

The State Department of Health shall, in turn, notify the appropriate local health department or agency in a timely manner, usually within the timeframe for reporting in Regulation 1, whenever it learns of a case of a disease reportable in Regulation 1 or it learns of an environmental exposure potentially threatening the public health.

These requirements shall not apply if the State and local health agencies mutually agree not to share information on reported cases.

Sharing of medical information on persons with reportable diseases or illnesses as defined in Regulation 1 between authorized personnel of State and local health departments shall be restricted to information necessary for the treatment, control, investigation, and prevention of environmental and chronic diseases dangerous to the public health.

Sharing of trade secrets; and confidential commercial, geological, or geophysical data shall be performed in a manner that preserves the confidentiality of the information.

Regulation 5. Reporting of Diseases Among Animals

Every veterinarian, livestock owner, veterinary diagnostic laboratory director, or other person having the care of, or knowledge of, the existence of animals having or suspected of having any disease resulting from exposure to known or suspected hazardous chemicals, radiologic materials, or biologic substances which may endanger the public health, shall promptly report the facts to the State or local health department or health agency.

Regulation 6. Confidentiality

All personal medical records and reports held by the state or local health department in compliance with these regulations shall be confidential information subject to C.R.S. 25-1-122(4). In addition, trade secrets and confidential commercial, geological, or geophysical data submitted to or held by the Colorado Department of Health in compliance with these regulations shall be confidential. This information is to be used by the Department as source material for necessary disease control efforts and the development of prevention programs. Reasonable efforts shall be made by the Department to consult with the attending physician or medical facility caring for the patient prior to any further follow-up by State or local health departments or health agencies.

Appendix A.

Reportable Birth Defects and Developmental Disabilities

[Listed conditions relate directly to ICD-9-CM codes
(International Classification of Diseases)]

Major congenital anomalies and chromosomal abnormalities	Infections
Congenital (perinatal) infections	Encephalitis
Congenital syphilis	Meningitis
Congenital rubella	
Cytomegalovirus	Injuries
Toxoplasmosis/herpes simplex	Traumatic brain injuries
Neonatal hepatitis	Spinal cord injuries
Sensory impairments	Other diagnoses
Hearing loss	Amniotic bands
Blindness and low vision	Cerebral cysts
	Cerebral lipidoses
Other disabilities	Child maltreatment syndrome
Specific delays in development	Chorioretinitis
Mental retardation	Convulsions/seizures
Infantile cerebral palsy	Drug withdrawal syndrome in the newborn
Autism spectrum disorders (ASD)	Failure to thrive
	Familial degenerative CNS disease
Genetic and endocrine/metabolic diseases	Infantile spasms
Hypothyroidism	Muscular dystrophies
Disorders of amino acid transport and metabolism	Noxious influences affecting fetus (includes Fetal Alcohol Syndrome)
Disorders of carbohydrate transport and metabolism	Renal tubular acidoses
Lipidoses	Retinal degeneration
Disorders of copper metabolism	Werdnig Hoffman disease
Cystic fibrosis	Intracranial hemorrhage
Other disorders of purine and pyrimidine metabolism	Birth trauma
Mucopolysaccharidosis	Slow fetal growth and fetal malnutrition
Sickle cell anemia	
Biotinidase deficiency	
Congenital adrenal hyperplasia	

Appendix B. Letter

STATE OF COLORADO

Bill Ritter, Jr., Governor
James B. Martin, Executive Director

Dedicated to protecting and improving the health and environment of the people of Colorado

4300 Cherry Creek Dr. S. Laboratory Services Division
Denver, Colorado 80246-1530 8100 Lowry Blvd.
Phone (303) 692-2000 Denver, Colorado 80230-6928
TDD Line (303) 691-7700 (303) 692-3090
Located in Glendale, Colorado
<http://www.cdphe.state.co.us>



Colorado Department
of Public Health
and Environment

Date:XXXX

Re: Laboratory Test Results dated XXXXXXXX

Dear Ms/Mr,

The Colorado Department of Public Health and Environment (the department) is getting in touch with persons who tested for a higher than normal level of mercury in their blood and/or urine¹. We have received your (or your child's) mercury test in XXX of XXXX and it shows a blood/urine mercury level of XX µg/L. **This result does not mean that you (or your child) have an urgent health concern, but it may show mercury exposure.**

We have developed a survey for persons with high blood and/or urine mercury levels. This survey is part of an effort to reduce your (or your child's) exposure to mercury and to help you avoid the possibility of future health impacts. Your answers to the survey questions will help us give you some suggestions for lowering your exposure to mercury. We also hope that by taking the survey, we can add to your awareness about how mercury could affect your health or the health of your family.

Your participation in this survey is voluntary. Any information you provide is kept strictly confidential. Parents should complete the survey for their children.

If you would like to take this survey, please pick one of the following options:

1. Fill out the enclosed survey and return it to the department in the envelope provided.
2. Call the department at XXX to schedule a time that works for you. Once a time has been scheduled, department staff will call you to answer the survey questions over the telephone.
3. Do nothing. The department staff will call you during business hours to complete this survey over the telephone.

If you have any questions, please contact _____ of the department at _____. Thank you for your assistance in this matter.

Sincerely,

¹ Colorado law requires laboratories to report test results with high levels of mercury in blood or urine.

Appendix C. Adult Telephone Questionnaire

Name of interviewer: _____ Interview date: _____

Name of patient: _____

Date of patient birth _____ Study ID # _____

TELEPHONE INTRODUCTION:

Hello, my name is XXXXX. I'm calling for Mr./Ms./Mrs. Is he/she in?

(NO) I'm calling from the Colorado Health Department. When is a good time to reach him/her? XXXXXXXX Please tell him/her I called. If he/she wishes to return my call, here is my phone number (toll free).

(YES) I'm calling from the Colorado Health Department. We are investigating sources or mercury exposures in the state and are interviewing people who have recently had blood tests for mercury. Recently we sent you a letter asking for your help with this investigation. Do you remember receiving the letter?

(YES) Good. I'd like to take a moment to describe what you can do to help.

(NO) My records show that I see that we mailed the letter to you on (date) to (address). Is that your correct address? If not, I will send you another copy of the letter. While I have you on the phone, let me explain briefly what the letter is about.

CONSENT: Laboratories are required to report clinical test results of mercury to the Colorado Department of Public Health and Environment. We follow up on these reports to investigate possible health problems associated with mercury so that we can take actions to reduce/prevent exposures. Sometimes this effort can also help prevent others from getting sick. We would like to ask you some questions about your potential sources of mercury exposure and your medical care. The questions take about XX minutes and you are free to decline to participate.

There is no risk or direct benefit to you and the facts we collect will be kept private to the level allowed by law. You may refuse to answer any questions or stop the survey at any time. You may contact the IRB chair at 303-692-2621 (Carol Stanton) if you have questions about your rights as a participant or Raj Goyal, if you have questions about the investigation. Do you have any questions for me?

Will you help us by participating in this questionnaire?

(YES) Great, may I:

Begin the questions now?

Call back at a specific time? (note time and date of callback)

(NO) I see. Is there any information I can provide that would ease your concerns?

BACKGROUND INFORMATION

1) I want to confirm the spelling of your name:

First _____ Middle _____
Last _____

2) Have you ever had a different Last Name (females only)?

Yes Other Last Name _____
No
Unknown
Refused

3) I want to confirm your address (only if they did not receive our letter):

Number & Street _____ City _____
State _____ Zip _____
Unknown
Refused

4) I want to confirm your home phone number:

() _____ - _____

5) I want to confirm your date of birth (mm/dd/yyyy)

Date _____
Unknown
Refused

6) How would you describe your race or ethnicity? The choices are (circle):

White
African American
Asian
Pacific Islander
Hispanic
Alaskan/American Indian
OTHER specify _____
Unknown
Refused

7) What is the highest level of education that you have completed (circle)?

7th grade or less
Some high school
High School Graduate
Some College or Technical School
College/ Technical School Graduate
Graduate Degree
Professional Degree

Unknown
Refused

8) Our records indicate that you had a blood/urine test for mercury on (date of test).
Were you ever notified of the result?

Yes
No
Unknown
Refused

9) Do you know why your doctor tested for mercury?

Yes explain/describe_____

No
Unknown
Refused

10) Why did you go to the doctor originally?

Explain/ describe_____

Unknown
Refused

11) Do you know how you were exposed to mercury?

Yes explain/describe_____

No
Unknown
Refused

12) Have you had any previous mercury testing in the last 5 years?

Yes explain/describe why_____

No
Unknown
Refused

13) Do you have another mercury test scheduled?

Yes
No
Unknown
Refused

14) When is your next mercury test scheduled for?

(approximate date) mm/dd/yyyy_____

15) Did your doctor identify any signs or symptoms of mercury exposure?

Yes – see next question and list below
No
Unknown

Refused

16) What signs or symptoms did your doctor identify (check all that apply)?

Signs/Symptoms					
headache		incoordination		metallic taste	
weakness		short-term memory loss		fever	
malaise		impaired sense of smell		rash	
blurred vision		leg cramps		insomnia	
social withdrawal		gingivitis		loss of appetite	
numbness/tingling		nephritic syndrome		irritability	
impaired hearing		renal failure		salivation	
tremor		proteinuria		depression	
Other (explain)					

OCCUPATIONAL HISTORY

17) What is your current occupation?

List/describe _____

Unknown

Refused

18) Where is your place of work (name / industry / location)?

List/describe _____

Unknown

Refused

19) In the last 2 years have you or someone in your household worked in the following places?

List/describe – insert information in table below

Unknown

Refused

Work Place	Self	Other (who?)	Job Title
Mine			
Dental Practice			
Electrical or electronic factory			
Laboratory			
Hospital or Doctors' Surgery			
Coal power plant or production process			
Industry making gas pressure regulators (gas meters)			
Waste disposal or incineration site			
Fluorescent tube or chemical production plant			
Chloralkali plant			
Thermometer manufacturing plant			
Crematory			
Any other place using mercury			

ENVIRONMENTAL EXPOSURES

20) How long have you lived at your current permanent address?

Number of years _____

Unknown

Refused

21) What type of home do you live in?

Single family, townhouse, duplex,

Mobile or modular home

Apartment or condominium

Other – Describe _____

Unknown

Refused

22) Are you aware of a mercury spill, including a broken thermometer or compact fluorescent lightbulb, in your home within the past year?

Yes

No

Unknown

Refused

23) When did this spill occur?

Date (mm/dd/yyyy) _____

Unknown

Refused

24) Who cleaned up the spill?

Name/relationship _____

Unknown

Refused

25) How was the spill cleaned?

Method used _____

Unknown

Refused

26) How often do you eat fish or seafood?

Less than once/month

About once/month

Less than once/week

About once/week

Few times/week

Daily

Unknown

Refused

27) Were you eating more or less fish or seafood before you saw your doctor and had the mercury test?

More Describe _____

Less Describe _____

No change

Unknown

Refused

28) What type of fish do you normally eat?

List/describe _____

Unknown

Refused

29) Where do the fish you eat normally come from?

Grocery store/restaurant

Caught

Unknown

Refused

30) If fish usually come from a *grocery store*, how is the fish packaged?

Canned

Fresh

Frozen

Unknown

Refused

31) If the fish is normally *caught*, where was the fish caught?

Ocean List/describe _____

River/stream List/describe _____

Lake List/describe _____

Unknown

Refused

32) Have you participated in any of the following activities recently?

List/describe (see table below)

Unknown

Refused

Activity or Practice	Interviewee	Other (who?)	Describe
Religious practices (azogue, Santeria, Espiritismo)			
Folk Medicine/ Herbal Remedies			
Antiques (clocks, mirrors, lamps)			
Outdated Medicine (laxatives, worming medications, teething powders)			
Photography development			
Broken thermometers/electrical switches			
Fluorescent light bulbs			

33) How many silver amalgam dental fillings do you have?

Number _____

Unknown

Refused

34) Have any of your fillings broken in the last 6 months?

Yes Number _____

No

Unknown

Refused

35) When did you last visit the dentist? _____ (mm/dd/yyyy)

FAMILY INFORMATION

36) Do you have any children younger than 7 who either live with you, or who frequently visit you?

- Yes
- No
- Unknown
- Refused

37) Have these children ever been tested for mercury?

- Yes Child's Name _____ Age _____
Result _____ (include units)
- No
- Unknown
- Refused

38) Is anyone in the house pregnant or nursing?

- Yes Pregnant _____ Nursing _____
- NO
- Unknown
- Refused

**Thank you for talking with me today. Do you have any questions?
(Record questions and answers provided)**

Appendix D. Child Telephone Questionnaire

Name of interviewer: _____ Interview date: _____

Name of patient: _____

Date of patient birth _____ Study ID # _____

TELEPHONE INTRODUCTION: Hello, my name is XXXXX and I'm calling for the parent or legal guardian of (Childs Name). Is he/she in?

(NO) I'm calling from the State Health Department. When is a good time to reach him/her? XXXXXXXX Please tell him/her I called. If he/she wishes to return my call, here is my phone number (toll free).

(YES) I'm calling from the Colorado Health Department. We are investigating sources or mercury exposures in the state and are interviewing people who have recently had blood tests for mercury. Recently we sent you a letter asking for your help with this investigation. Do you remember receiving the letter?

(YES) Good. I'd like to take a moment to describe what you can do to help.

(NO) My records show that I see that we mailed the letter to you on (date) to (address). Is that your correct address? If not, I will send you another copy of the letter. While I have you on the phone, let me explain briefly what the letter is about.

CONSENT: Laboratories are required to report clinical test results of mercury to the Colorado Department of Public Health and Environment. We follow up on these reports to investigate possible health problems associated with mercury, so we can take actions to reduce/prevent exposures. Sometimes this effort can also help prevent others from getting sick. According to a laboratory report, CHILD NAME _____ had a mercury test, and you have been identified as the child's parent or guardian. In order for us to do our investigation we need some information from you about your child. We would like to ask you some questions about the potential sources of mercury exposure and your child's medical care. The questions take about XX minutes and you are free to decline to participate.

There is no risk or direct benefit to you and the facts we collect will be kept private to the level allowed by law. You may refuse to answer any questions or stop the survey at any time. You may contact the IRB chair at 303-692-2621 (Carol Stanton) if you have questions about your rights as a participant or Raj Goyal, if you have questions about the investigation. Do you have any questions for me at this time?

Will you help us by participating in this questionnaire?

(YES) Great, may I:

Begin the questions now?

Call back at a specific time? (note time and date of callback)
(NO) I see. Is there any information I can provide that would ease your concerns?

BACKGROUND

- 1) Could you please confirm the following information?
- a. Childs first name _____ b. Childs middle name _____
 - c. Childs last name _____
 - d. Childs primary address:
Number and Street _____
City, State _____
 - e. Alternate address (?):
Number and Street _____
City, State _____
 - f. Primary phone number () _____
 - g. Alternate phone # (if applicable) () _____
 - h. Childs Date of Birth (mm/dd/yyyy) _____
 - i. Childs gender _____
 - j. Primary care physician contact information, if changed _____

2) How long has your child lived at this address? If less than 6 mos., previous address?
Number and Street _____ City _____
State _____ Zip _____

- 3) How would you describe you child’s race or ethnicity?
- White
 - African American
 - Asian
 - Hispanic
 - Pacific Islander
 - Alaskan/American Indian
 - Other
 - Unknown
 - Refused

4) Our records indicate that your child had a mercury test in _____ and the result was _____ . Were you aware of the result?

- a. Yes
- b. No
- c. Refused

5) Do you know why the doctor ordered this test?

- a. Yes
- b. No
- c. Refused

6) Does your child have another mercury test scheduled?

- a. Yes Date: _____(mm/dd/yyyy)
- b. No
- c. Unknown
- d. Refused

7) Why did your child go to the doctor originally?

- a. Explain _____
- b. Unknown
- c. Refused

8) Did the doctor identify any of the following signs or symptoms?

Signs/Symptoms			
headache		incoordination	metallic taste
weakness		short-term memory loss	fever
malaise		impaired sense of smell	rash
blurred vision		leg cramps	insomnia
social withdrawal		gingivitis	loss of appetite
numbness/tingling		nephritic syndrome	irritability
impaired hearing		renal failure	salivation
tremor		proteinuria	depression
Other (explain)			

9) Are you aware of any potential sources of mercury or know how your child was exposed?

- a. Yes Explain _____
- b. No
- c. Unknown
- d. Refused

10) Has your child had any previous mercury testing within the last 5 years?

- a. Yes, Date _____
- b. No
- c. Unknown
- d. Refused

ENVIRONMENTAL EXPOSURES

11) Did the mother of the child have any mercury tests while pregnant or breastfeeding (if child is less than 1 year)?

- a. Yes, Result _____ Units ____
- b. No
- c. Unknown
- d. Refused

12) Has anyone else in your family been tested for mercury?

- a. Yes _____
- b. No
- c. Unknown
- d. Refused

13) Has your child ever been tested for any other heavy metals, such as lead?

- a. Yes
- b. No
- c. Unknown
- d. Refused

14) Are you aware of any mercury spills, including broken thermometers, dial thermostats, CFL breakages, in the child's residence within the past year?

- a. Yes
- b. No
- c. Refused

15) Are of aware of any other potential exposures to mercury such as your child playing with quicksilver?

- a. Yes
- b. No
- c. Refused

16) Does your child use any herbal supplements, folk medicines, food supplements, or alternative medicines?

- a. Yes Please list in table below (check all that apply)
- b. No
- c. Unknown
- d. Refused

Activity or Practice	Child	Other (who?)	Describe
Religious practices (azogue, Santeria, Espiritismo)			
Folk Medicine/ Herbal Remedies			
Antiques (clocks, mirrors, lamps)			
Outdated Medicine (laxatives, worming medications, teething powders)			
Photography development			
Broken thermometers/electrical switches			
Fluorescent light bulbs			

17) How often did your child eat fish or seafood in the two months prior to the mercury analysis?

- a. Never
- b. Less than once a month
- c. About once a month
- d. A couple of times a month
- e. About once a week
- f. Few times per week
- g. Daily
- h. Unknown
- i. Refused

18) What types of fish or seafood does your child typically eat and where does it come from?

19) Are there any other children or pregnant/breastfeeding women that you are aware of who may also have been exposed to mercury at the same time as your child? Have they been tested?

- a. Yes
- b. No
- c. Unknown
- d. Refused

**Thank you for talking with me today. Do you have any questions?
(Record questions and answers provided)**

Appendix E. Toxfacts about Mercury



MERCURY
CAS # 7439-97-6

Agency for Toxic Substances and Disease Registry ToxFAQs

April 1999

This fact sheet answers the most frequently asked health questions (FAQs) about mercury. For more information, call the ATSDR Information Center at 1-888-422-8737. This fact sheet is one in a series of summaries about hazardous substances and their health effects. It's important you understand this information because this substance may harm you. The effects of exposure to any hazardous substance depend on the dose, the duration, how you are exposed, personal traits and habits, and whether other chemicals are present.

HIGHLIGHTS: Exposure to mercury occurs from breathing contaminated air, ingesting contaminated water and food, and having dental and medical treatments. Mercury, at high levels, may damage the brain, kidneys, and developing fetus. This chemical has been found in at least 714 of 1,467 National Priorities List sites identified by the Environmental Protection Agency.

What is mercury?

(Pronounced mĕr'kyə-rē)

Mercury is a naturally occurring metal which has several forms. The metallic mercury is a shiny, silver-white, odorless liquid. If heated, it is a colorless, odorless gas.

Mercury combines with other elements, such as chlorine, sulfur, or oxygen, to form inorganic mercury compounds or "salts," which are usually white powders or crystals. Mercury also combines with carbon to make organic mercury compounds. The most common one, methylmercury, is produced mainly by microscopic organisms in the water and soil. More mercury in the environment can increase the amounts of methylmercury that these small organisms make.

Metallic mercury is used to produce chlorine gas and caustic soda, and is also used in thermometers, dental fillings, and batteries. Mercury salts are sometimes used in skin lightening creams and as antiseptic creams and ointments.

What happens to mercury when it enters the environment?

- Inorganic mercury (metallic mercury and inorganic mercury compounds) enters the air from mining ore deposits, burning coal and waste, and from manufacturing plants.
- It enters the water or soil from natural deposits, disposal of wastes, and volcanic activity.

- Methylmercury may be formed in water and soil by small organisms called bacteria.
- Methylmercury builds up in the tissues of fish. Larger and older fish tend to have the highest levels of mercury.

How might I be exposed to mercury?

- Eating fish or shellfish contaminated with methylmercury.
- Breathing vapors in air from spills, incinerators, and industries that burn mercury-containing fuels.
- Release of mercury from dental work and medical treatments.
- Breathing contaminated workplace air or skin contact during use in the workplace (dental, health services, chemical, and other industries that use mercury).
- Practicing rituals that include mercury.

How can mercury affect my health?

The nervous system is very sensitive to all forms of mercury. Methylmercury and metallic mercury vapors are more harmful than other forms, because more mercury in these forms reaches the brain. Exposure to high levels of metallic, inorganic, or organic mercury can permanently damage the brain, kidneys, and developing fetus. Effects on brain functioning may result in irritability, shyness, tremors, changes in vision or hearing, and memory problems.

Short-term exposure to high levels of metallic mercury vapors may cause effects including lung damage, nausea,

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES, Public Health Service
Agency for Toxic Substances and Disease Registry

ToxFAQs Internet address via WWW is <http://www.atsdr.cdc.gov/toxfaq.html>

vomiting, diarrhea, increases in blood pressure or heart rate, skin rashes, and eye irritation.

How likely is mercury to cause cancer?

There are inadequate human cancer data available for all forms of mercury. Mercuric chloride has caused increases in several types of tumors in rats and mice, and methylmercury has caused kidney tumors in male mice. The EPA has determined that mercuric chloride and methylmercury are possible human carcinogens.

How can mercury affect children?

Very young children are more sensitive to mercury than adults. Mercury in the mother's body passes to the fetus and may accumulate there. It can also pass to a nursing infant through breast milk. However, the benefits of breast feeding may be greater than the possible adverse effects of mercury in breast milk.

Mercury's harmful effects that may be passed from the mother to the fetus include brain damage, mental retardation, incoordination, blindness, seizures, and inability to speak. Children poisoned by mercury may develop problems of their nervous and digestive systems, and kidney damage.

How can families reduce the risk of exposure to mercury?

Carefully handle and dispose of products that contain mercury, such as thermometers or fluorescent light bulbs. Do not vacuum up spilled mercury, because it will vaporize and increase exposure. If a large amount of mercury has been spilled, contact your health department. Teach children not to play with shiny, silver liquids.

Properly dispose of older medicines that contain mercury. Keep all mercury-containing medicines away from children.

Pregnant women and children should keep away from

rooms where liquid mercury has been used.

Learn about wildlife and fish advisories in your area from your public health or natural resources department.

Is there a medical test to show whether I've been exposed to mercury?

Tests are available to measure mercury levels in the body. Blood or urine samples are used to test for exposure to metallic mercury and to inorganic forms of mercury. Mercury in whole blood or in scalp hair is measured to determine exposure to methylmercury. Your doctor can take samples and send them to a testing laboratory.

Has the federal government made recommendations to protect human health?

The EPA has set a limit of 2 parts of mercury per billion parts of drinking water (2 ppb).

The Food and Drug Administration (FDA) has set a maximum permissible level of 1 part of methylmercury in a million parts of seafood (1 ppm).

The Occupational Safety and Health Administration (OSHA) has set limits of 0.1 milligram of organic mercury per cubic meter of workplace air (0.1 mg/m³) and 0.05 mg/m³ of metallic mercury vapor for 8-hour shifts and 40-hour work weeks.

References

Agency for Toxic Substances and Disease Registry (ATSDR). 1999. Toxicological profile for mercury. Atlanta, GA: U.S. Department of Health and Human Services, Public Health Service.

Where can I get more information? For more information, contact the Agency for Toxic Substances and Disease Registry, Division of Toxicology, 1600 Clifton Road NE, Mailstop F-32, Atlanta, GA 30333. Phone: 1-888-422-8737, FAX: 770-488-4178. ToxFAQs Internet address via WWW is <http://www.atsdr.cdc.gov/toxfaq.html>. ATSDR can tell you where to find occupational and environmental health clinics. Their specialists can recognize, evaluate, and treat illnesses resulting from exposure to hazardous substances. You can also contact your community or state health or environmental quality department if you have any more questions or concerns.

