

**Rocky Mountain Arsenal Medical Monitoring Program**  
*Surveillance for Birth Defects*  
**Compendium**

Prepared by:  
Colorado Department of Public Health and Environment

May 2010



---

**Colorado Department  
of Public Health  
and Environment**

**For More Information, Contact:**

**Russel Rickard**  
**Disease Control & Environmental Epidemiology Division**  
**Colorado Department of Public Health & Environment**  
**4300 Cherry Creek Drive South**  
**Denver, Colorado 80246**  
**303-692-2623**  
**[russel.rickard@state.co.us](mailto:russel.rickard@state.co.us)**

## **Table of Contents**

Acknowledgements.....	2
Background.....	3
Objectives/Methods.....	4
Results .....	9
Conclusions .....	13
Lessons Learned .....	13
References.....	15
Appendix A: Description of Colorado Responds to Children with Special Needs.....	16
Appendix B. Maternal Demographics of Births in the RMA Study Area: 1989-1996...	18

## **Acknowledgements**

The Rocky Mountain Arsenal Medical Monitoring Program: *Surveillance for Birth Defects* was funded by The Department of the Army.

We would like to gratefully acknowledge the following individuals for their contributions to the project and its dissemination: Amy Alman, Kirk Bol, Dion Chilberg, Janice Rinsky-Eng, Carol Garrett, Julia Korndorfer, Jo Matson, Lisa Miller, Jane Mitchell, April Montgomery, Barbara Nabors, Heather Orton, Margaret Rutenber, Carol Stanton, Rickey Tolliver, Cynthia Vogel, Mike Wilson, members of the Rocky Mountain Arsenal Medical Monitoring Advisory Group (MMAG) and the Rocky Mountain Arsenal Citizens Advisory Board (CAB).

## Background

The Rocky Mountain Arsenal (RMA) is located approximately 10 miles northeast of downtown Denver and covers 27 square miles in southern Adams County. The US Army established the Arsenal in 1942 to manufacture chemical and explosive weapons. From the late 1940s to early 1980s, some of the Arsenal was leased to private companies, most notably Shell Oil Company. These companies made insecticides, herbicides and other agricultural chemicals. All production at the Arsenal ceased in 1982. In 1996, the Army, the Colorado Department of Public Health and Environment and the US Environmental Protection Agency reached an agreement about how the cleanup of contamination left over for those earlier years would take place.

The U.S. Army, the U.S. Environmental Protection Agency (EPA) and the Colorado Department of Public Health and Environment on June 11, 1996 signed the On-Post Record of Decision (ROD), which describes the selected remedial action for the Rocky Mountain Arsenal cleanup, with concurrence of the U.S. Fish and Wildlife Service and Shell Oil Company. The ROD stipulated that a medical monitoring advisory group be formed to evaluate information concerning exposure pathways, to identify and recommend appropriate public health actions and to communicate this information to the community. Recommendations adopted by the Rocky Mountain Arsenal Medical Monitoring Advisory Group (MMAG) defined the goals, objectives and methods of a health surveillance program designed to respond effectively to Arsenal-related health concerns expressed by the community and Citizens Advisory Board (CAB).

One of the goals identified by the MMAG in 1998 was to enhance community assurance that exposure prevention measures during the Arsenal soil cleanup were effective. One method recommended by the advisory group was the collection and publication of health indicator data, including the frequency of birth defects in communities surrounding the Arsenal.

Per recommendations in the RMA document *Surveillance for Birth Defects*, the birth defects surveillance component of the Medical Monitoring Program relied on the State Health Department's existing birth defects registry, within Colorado Responds to Children with Special Needs (CRCSN), to monitor birth defects in the communities surrounding the Arsenal (See Appendix A).

The principal goals for this surveillance system were identified as: 1) Establish baseline rates of birth defects; 2) monitor rates for temporal or spatial changes from the baseline; 3) provide early intervention and support-service referrals to families of children with birth defects; and 4) investigate increased rates of birth defects.

This report summarizes birth defect surveillance activities conducted using data available from 1989 through March 2009. The time period was selected to encompass all cases reported to CRCSN until nine months after the completion of on-site soil remediation activities at the RMA.

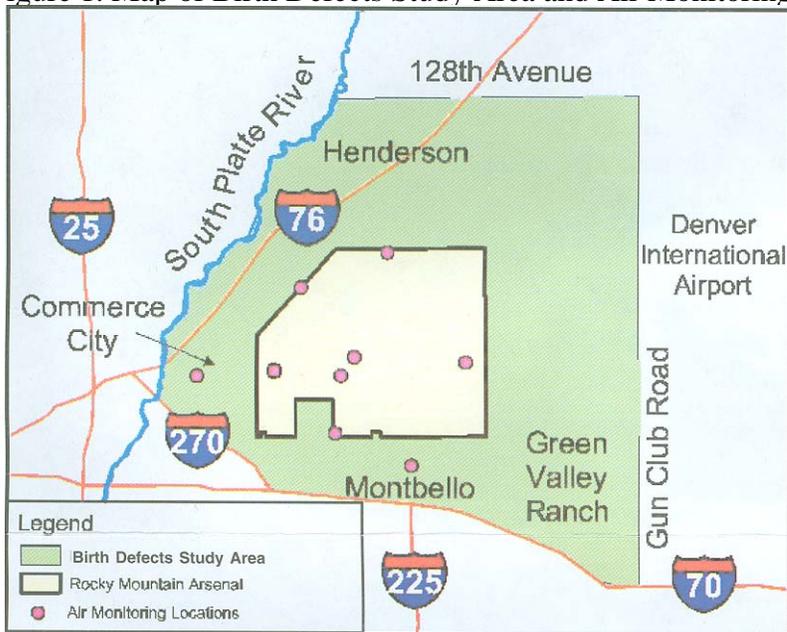
## Objectives/Methods:

### Objective 1: Establish baseline rates for birth defects occurring in the communities surrounding the Rocky Mountain Arsenal

#### Selection of geographic boundaries that define communities surrounding the RMA

The RMA Medical Monitoring Program staff in conjunction with CRCSN staff selected the geographic boundaries for birth defects surveillance activities. Factors considered during boundary selection included the potential for exposure, adequate numbers for meaningful statistical analysis and elimination of the risk of diluting an observable effect. The geographic boundaries were defined as follows: the eastern boundary was defined as Gun Club Road extending north from Interstate 70 to 128th Avenue, the northern boundary was defined by 128th Ave west to the South Platte River, the western boundary followed the course of the South Platte River south to Interstate 270 and the southern border was defined by Interstate 270 and Interstate 70 to Gun Club Road (see Figure 1).

Figure 1. Map of Birth Defects Study Area and Air Monitoring Locations



*Note: It was noted in this process that appropriate monitoring of the possible effects of an exposure incident, if one occurred, might necessitate redefining the geographic area of concern. As a result, the birth defects monitoring protocol included a surveillance method with the capability to adjust to boundary changes with minimal modifications.*

### Defining the baseline time period:

Optimal features of a “baseline time period” include: a time period with no known exposure incidents and a long enough time period to determine a statistically stable baseline rate. CRCSN began statewide surveillance for birth defects in 1989 and RMA cleanup activities began in 1997. Therefore the time period 1989-1996 was chosen as the baseline time period because it provided the most data available to establish baseline rates during a period when there were no known exposure incidents.

### Defining the data needed for analysis

To calculate baseline rates of birth defects, it was necessary to identify when congenital anomalies occurred to children born to women living in the study area (event type 1) and when congenital anomalies did not occur to children born to women living in the study area (event type 2). CRCSN collects information on the occurrence of congenital anomalies for the entire state of Colorado and therefore was the source of event type 1 data. The Center for Health and Environmental Information and Statistics (CHEIS) at the Colorado Department of Public Health and Environment is the source of Colorado vital statistics which are derived from vital records such as birth certificates. CHEIS therefore was the source of demographic information for both event type 1 and 2. By identifying these two types of data, birth defect rates could be calculated.

### Identifying births occurring in the communities surrounding the RMA

CHEIS maintains the registration of Colorado vital records. A mother’s residence street address at the time of the birth is recorded on Colorado vital records. A longitude and latitude point was generated from this street address that represented its exact location. Once these data were plotted on a map, the study area boundaries were overlaid and births occurring outside of the defined boundaries were eliminated from analysis. This geocoding process enabled the monitoring system to respond to study area boundary changes if requested.

### Statistical estimation of baseline rates

To estimate a baseline rate, it is necessary to consider any significant trends in the data. The estimated baseline rate needs to be adjusted according to whether or not there is a statistically significant trend and whether the trend is increasing or decreasing. Therefore, before establishing baseline rates for the congenital anomalies being monitored in the RMA study area, the data were first tested for statistically significant trends (either increasing or decreasing).

In conjunction with the MMAG and the CAB, specific groups of congenital anomalies were identified and the data for each were tested for statistically significant trends during the baseline time period using a method that compares rates between samples that are quantitatively ordered [Fleiss, 1973]. This method tests the following hypotheses: 1) there is no statistically significant association between the rates and year of birth, 2) there is a linear association between the rates and year of birth and 3) the slope of the line fitted to the data is not different from zero.

When there was no statistically significant trend in the data, the overall live birth prevalence rate for the seven years combined (1989-1996) was to be used as the baseline rate for that particular anomaly or group of anomalies. If a statistically significant trend was found in the data, the average rate was to be adjusted according to whether the trend was increasing or decreasing.

The MMAG and the CAB also requested a descriptive analysis of several maternal demographic variables (age at birth, race/ethnicity, marital status, and number of prenatal visits) for the RMA resident birth population during the baseline time period.

## **Objective 2: Describe and analyze rates for significant temporal changes during and after clean-up activities**

Birth defects surveillance consisted of routinely monitoring birth defect rates over time. For communities surrounding the RMA, interest was in detecting increases in rates above baseline that warranted further investigation.

To accomplish this task, CRCSN was to use the cumulative sum (CUSUM) technique [Lucas, 1985] to detect statistically significant increases in birth defects rates. Basically, this procedure will “flag” a time period when a specified increase in a rate exceeds random fluctuation. All “flags” were to be investigated under the CRCSN investigative protocol (See Objective 5).

Under the guidance of the Medical Monitoring Advisory Group, and based on both statistical considerations and what was learned about the occurrence of birth defects from the baseline assessment, it was decided that CUSUM monitoring schemes would be designed for the following groups of diagnostic categories:

- Total Congenital Anomalies
- Major Congenital Anomalies (anomalies of medical, surgical or cosmetic importance)
- Heart Defects (total and major)
- Muscle and Skeletal defects (total and major)
- Kidney and Bladder defects (total and major)

Birth defects data were updated and statistical monitoring performed for each quarter of the year. During these quarterly reviews, all historical data were reexamined to incorporate any new data not available at the time of the quarterly analyses.

### **Objective 3: Describe and analyze spatial occurrence of birth defects and normal birth outcomes in these communities**

Longitude and latitude points were generated from the mothers' residence street addresses at the time of event. If a CUSUM "flag" occurred, denoting a possible increase in the rate of a birth defect (see Objective 2), these spatial data were used to determine if an increase could be connected to a specific geographic location in the study area. This determination was made by using the spatial scan statistic developed by Kulldorf and Nagarwalla (1995). This methodology was chosen because of its superior capability to use point data, which directly addressed the public concern about how to evaluate the geographic distribution of birth defects without having to use administrative (such as zip codes) or political (such as census tracts) boundaries.

### **Objective 4: Connect families of children with birth defects in these communities to early intervention and support services**

The primary aim of the CRCSN Community Notification and Referral Program is the prevention of secondary disabilities in children by connecting their families with services and support in their local communities. Examples of the many types of services available to families are Special Supplemental Food Programs for Women, Infants and Children (WIC), immunization clinics, well-child clinics, grief counseling, parent support groups, Supplemental Security Income (SSI), specialty medical clinics, early intervention programs and developmental clinics. As with other reportable disease data and their use, confidentiality and privacy were carefully protected throughout the referral process.

At the beginning of each month, CRCSN determined if any birth defect cases had been reported in the study area. These cases were subdivided into two categories. The first set was all congenital anomalies and medical risk factors for developmental delay reported to CRCSN on a birth certificate. Information from the birth certificate is protected by Board of Health regulations and cannot be shared without permission. The families of these cases were sent a negative consent letter regarding the Community Notification and Referral Program. If this letter was not returned to CRCSN, the child was included in the referral program; if the letter was sent back to CRCSN or was un-deliverable by the post office, the child was not included in the referral program. The second set of CRCSN cases was comprised of all other congenital anomalies and medical risk factors for delay that were reported by some other data source besides the birth certificate, predominantly hospital discharge data. Board of Health Regulations allow the state health department and local health agencies to share information collected under disease reporting regulations including information related to birth defects. Therefore, information on these cases was shared directly with the local agencies without going through a negative consent process.

Local health department personnel, community nursing services, or Early Childhood Connections would then attempt to contact families by phone or a home visit to discuss their needs and inform them of available services.

Conditions reported to CRCSN that have been recognized as not needing medical intervention or as having a very low probability of needing services were screened out, so

information on children with these conditions was not sent to the local agencies. Families of children with minor conditions expressed their concern and sometimes alarm that a local agency was contacting them when they did not think their child had a problem. In addition, contacting and counseling families is a labor- and time-intensive process. Local public health agencies requested that they not receive information on cases with a low probability of needing their services.

**Objective 5: Use pre-established, scientifically sound criteria to determine the need for and type of appropriate follow-up investigations, based on the findings of Objectives 2 and 3**

A variety of follow-up actions typically are considered by CRCSN and tiered according to the strength of the findings of the information subsequently collected. For example, an initial follow-up of a finding meeting the criteria of statistical significance could include a medical records review of reported information. Another early follow-up action may include residence determination for the mother during gestation to ascertain whether residence history is a potentially important factor (i.e., did the mother live in the vicinity of the RMA during her pregnancy?).

A higher tier of follow-up may be referral of the observation to an independent ad hoc expert panel for review and recommendations to CDPHE (e.g. initiation of a case-control study).

CRCSN has an internal team assembled to review and investigate potential birth defects clusters: a medical epidemiologist, a medical information expert, a genetic counselor and two statistical analysts. If necessary, CRCSN also would consult with medical specialists on specific cases; for example, medical geneticists may be called upon to provide their expertise. In addition to medical specialists, CRCSN staff could seek advice from the staff of the Birth Defects and Genetics Diseases Branch of the Centers for Disease Control and Prevention (CDC). CRCSN is an active component of National Birth Defects Prevention Network, a network of specialists and experts available for consultation.

## Results

A total of 7,505 children were identified as born to women residing in the RMA study area from 1989-1996. The following descriptors were determined for this baseline population:

- The mean age of the mothers residing in the RMA study area was 25 years (median=24). The mean age for the same time period for the entire state of Colorado was 27.1 years (median=27). This difference was statistically significant ( $p<.01$ ); the 95 percent confidence interval (CI) for the difference is (-2.3, -1.97). A chi-square test that compared the age groups of the mothers also indicated that the mothers in the RMA study area were significantly younger than all mothers in Colorado ( $p<.01$ ).
- There was a higher percent of White/Hispanic and Black mothers residing in the RMA study area than in the entire state of Colorado ( $p<.01$ ).
- The mean level of education completed by mothers residing in the RMA study area was 11.8 years (median=12.). The mean level of education for the same time period for all mothers in Colorado was 13.1 years (median=12). This difference was statistically significant ( $p<.01$ ); the 95 percent CI for the difference is (-1.35, -1.25). A chi-square test that compared the education level groups of the mothers also indicated that the mothers in the RMA study area had significantly lower levels of education than all the mothers in Colorado ( $p<.01$ ).
- With respect to marital status at the time of the birth, fewer mothers residing in the RMA study area were married than in the entire state of Colorado ( $p<.01$ ).
- The mean number of prenatal visits for the mothers residing in the RMA study area was 10.8 (median=11). The mean number of prenatal visits for the same time period for all mothers in Colorado was 11.6 (median=12). This difference was statistically significant ( $p<.01$ ); the 95 percent CI for the difference is (-0.88, -0.64). A chi-square test that compared the number of prenatal visits also indicated that the mothers in the RMA study area had significantly fewer prenatal visits than all the mothers in Colorado ( $p<.01$ ).

Graphs for categorical analysis are presented in Appendix B.

Rates of birth defects remained stable over the baseline period. There was no evidence to suggest an elevated occurrence of birth defects in the study area during the baseline time period when compared to what occurred in the state as a whole during the same time period. Table 1 shows the rates of the common birth defects and how their rates in the RMA study area compared with the Colorado state rate during that same time period.

**Table 1. Baseline Rates of Congenital Anomalies in RMA Study Area versus Colorado Residents**

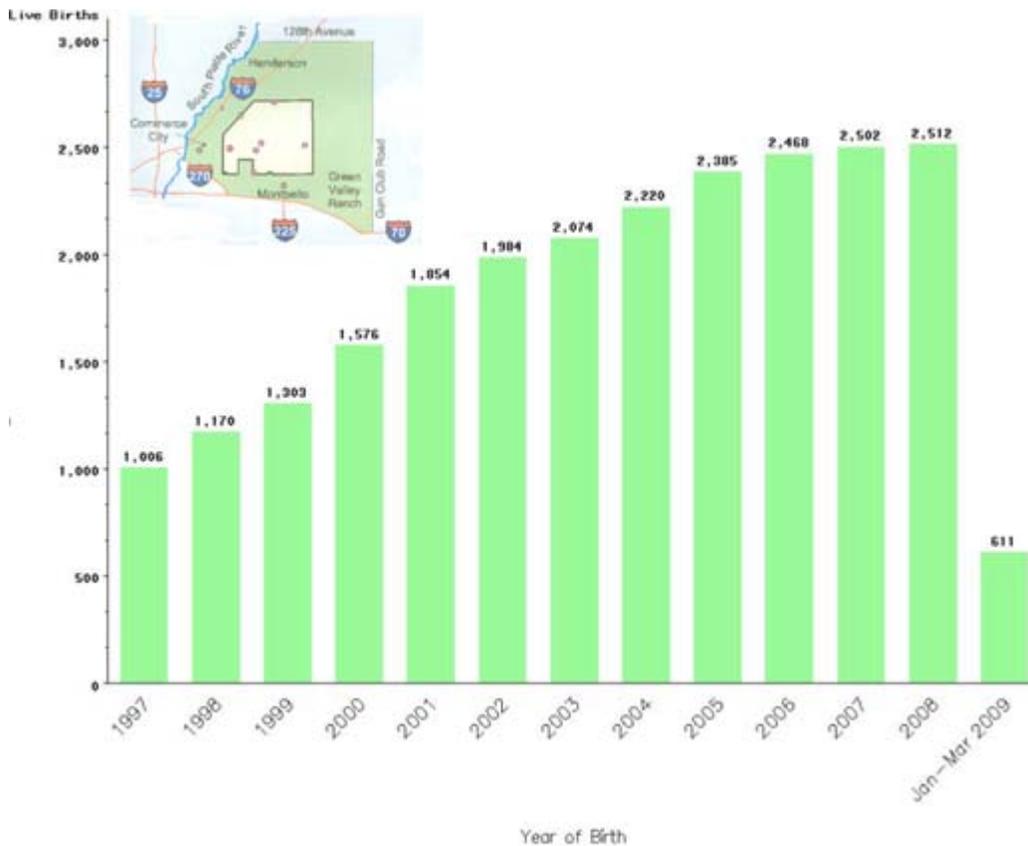
Rate per 10,000 live births	<i>RMA Study Area</i> 1989-1996 7,505 live births			Colorado 1989-1996 432,651 live births
Diagnosis Category	Lower	Rate	Upper	Rate
<b>Major Congenital Anomalies*</b>	450.19	<b>498.33</b>	550.01	<b>472.85</b>
<b>Heart Defects</b>	125.46	<b>151.90</b>	182.20	<b>149.57</b>
<b>Muscle and Skeletal defects</b>	131.53	<b>158.56</b>	189.45	<b>150.63</b>
<b>Kidney and Bladder defects</b>	120.61	<b>146.57</b>	176.39	<b>138.52</b>

\*Anomalies of medical, surgical or cosmetic importance

The column titled “Rate” is the actual point *estimate* of the rate calculated from the data. The columns entitled “Lower” and “Upper” are *the 95 percent confidence interval* for the point estimate. Essentially, we state that 95 times out of a hundred the manner in which we calculated this confidence interval would contain the *true* value of the rate if complete ascertainment were possible. If one were to compare just the point estimates in the RMA study area versus the point estimate of the state as a whole, the point estimates are numerically higher; however all of the state point estimates are contained within the confidence interval calculated for the RMA point estimates. This comparison provides evidence that RMA rates were not statistically elevated when compared to the state rates.

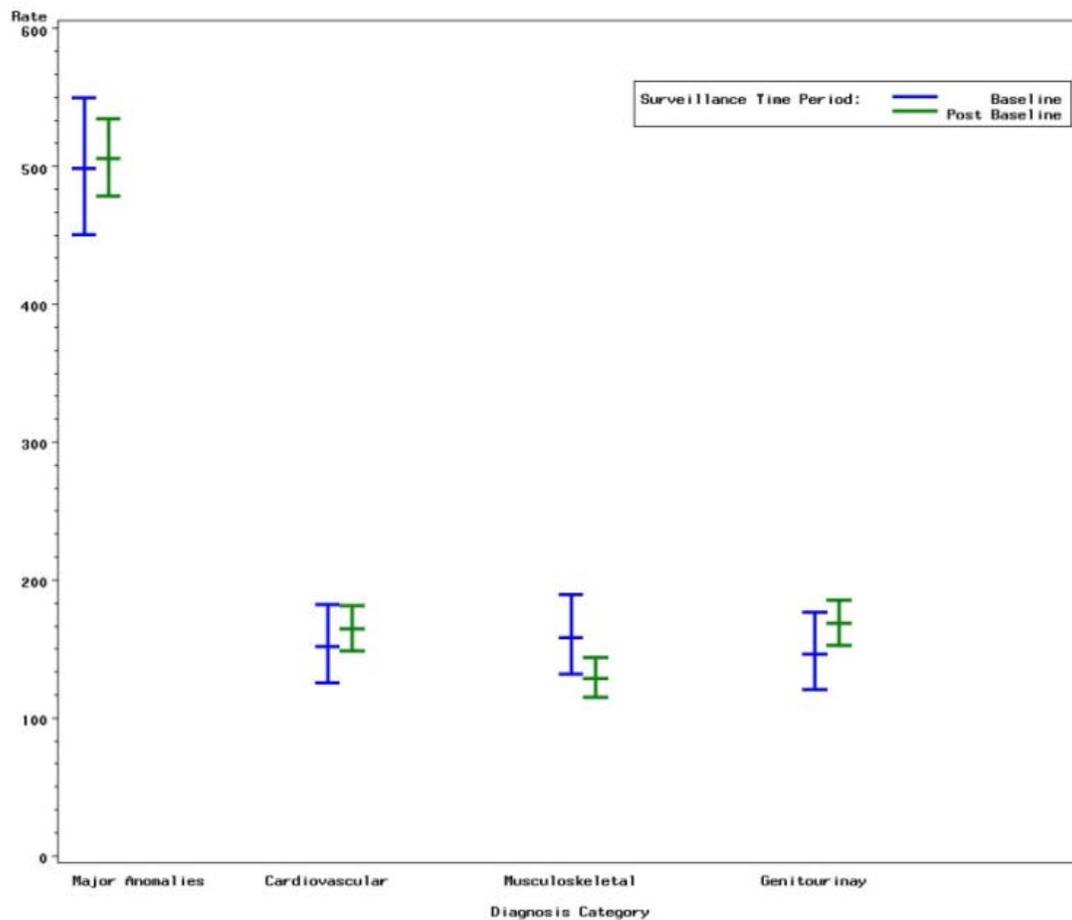
From 1997 to March of 2009, 23,665 children were identified as born to women residing in the RMA study area (See Figure 2). Data for the time period January through March 2009 were based on provisional data available from CHEIS at the time the quarterly report was prepared.

Figure 2. Live births Identified in the RMA Study Area: 1997-March 2009



Each quarter, CRCNS ran an extensive space and time analysis of data available from 1997 through March 2009. Results from these quarterly analyses were published on the Rocky Mountain Arsenal Website, noted in “Health Matters” newsletters and presented at CAB meetings. Actual address location (see Objective 3) was utilized in spatial analysis. Temporal monitoring was conducted on monthly rates (See Objective 2). To protect confidentiality of the citizens of the RMA study area, the Colorado Department of Public Health and Environment Data Release Policy does not allow release of data at this level. All significant statistical results obtained during the monitoring period were resolved upon medical record review. Overall, it can be concluded that there were no indications that rates have increased above the baseline rates beyond that expected due to random fluctuations. No statistically significant spatial clusters in the study area were identified. Overall estimation of baseline versus post baseline rates are presented in Figure 3.

Figure 3. Rates of Congenital Anomalies in RMA Study Area: Baseline and Post Baseline



CRCSN informed Colorado public health and early childhood agencies of children identified with birth defects, developmental disabilities, or risks for developmental delay. The agencies accepting the referral of children in the RMA area changed during different periods over the years. Conditions eligible for CRCSN include established medical diagnoses such as major congenital anomalies and chromosomal abnormalities, sensory impairments, genetic and metabolic diseases; medical risk factors for developmental delay such as infections, injuries, other diagnoses, prematurity and low birth weight. Until January 2003 two environmental risks for developmental delay, maternal age 15 years or less and maternal education less than 12 years in combination with no prenatal visits, were included in the notification program. These maternal risk factors were discontinued at the request of the local agencies because they could not offer effective interventions for the families. The total number of referrals provided over the course of the birth defects surveillance project is shown in Table 2.

Table 2. Community Notification Referral Program

<b>Month of Referral</b>	<b>Number of Children Referred to Local Agencies</b>
November 1998-December 1999	70
January-December 2000	86
January-December 2001	111
January-December 2002	117
January-December 2003	100
January-December 2004	146
January-December 2005	124
January-December 2006	121
January-December 2007	199
January-December 2008	248
January-December 2009	157

## **Conclusions**

No statistically significant geographic clusters were identified in the study area for any of the birth outcomes tracked over the course of the RMA birth defects surveillance project. There are no indications that rates have increased above the baseline rates, beyond that expected due to random fluctuations.

The time period of this study was selected to coincide with soil cleanup activities at the RMA. Adverse birth outcomes reported from the time site cleanup began in 1997 through March 2009 are not likely to be related to RMA cleanup activities because focused air monitoring conducted during cleanup has not shown ongoing or substantial off-site release that would cause significant exposure to surrounding communities for RMA chemicals.

## **Lessons Learned**

The primary goal of the Rocky Mountain Arsenal Medical Monitoring Program Surveillance for Birth Defects Project was to address community concern about the occurrence of birth defects during and after remediation activities. The following advantages of the initial approach to achieve this task were noted: 1) reliable data sources already existed, 2) baseline data was available for comparison to future data, 3) multiple reporting methods were already in place as well as authorized access to medical records to provide an improved surveillance methodology that was not susceptible to recall/reporting bias noted in earlier RMA health studies where data were self-reported, 4) the ability to identify all resident births occurring in the study area would overcome the low participation rates noted as a limiting factor in earlier RMA health studies, 5) expertise in medical record review and disease investigation was already established in the Disease Control and Environmental Epidemiology Division at CDPHE, 6) the

statistical methodology/analysis plan was in place and agreed upon prior to data collection and 7) the plan provided for multiple levels of data review and tiered follow-up.

Despite these strengths, addressing and adapting to situations that occurred throughout the course of this project was crucial to its completion. Some of the key lessons learned are summarized below.

All available geographic data are not equal. Although self-reported cities and counties of residence were available on the birth certificate, errors in self-reporting did occur. It was necessary to geocode the maternal residence street address to a longitude-latitude point to accurately determine where births occurred.

Although it is critical to have an analysis plan in place prior to collecting data, that plan may have to change over time. For example, the temporal monitoring analysis initially proposed and agreed upon utilized CUSUM techniques. As more data were collected each quarter, there were times when the assumptions about the distribution of the data [in order to have the CUSUM be a valid test] were not met. In these situations, other suitable methods were utilized. Changes in methodology were noted and posted on web site updates and in progress reports.

An additional issue of note is that only well-defined disease categories should be included in this type of monitoring effort. One of the initial categories chosen for monitoring purposes in this project was “Total Anomalies.” The initial rationale to include the category was to address the occurrence of minor anomalies. Over time, it was discovered that the reporting of minor anomalies across the state is unreliable and continues to be problematic.

In communities surrounding a perceived potential health hazard, the citizens’ primary concern is the potential for being exposed to an agent that may endanger their health. In this instance, the focus was on being exposed to an agent that causes a birth defect (a teratogen). The likelihood of any observed impact on the rate of birth defect outcomes, should exposure to a teratogen occur, is dependent on: 1) the frequency of exposure in the population to the agent at the critical embryonic time, 2) the strength of the teratogen, and 3) the proportion of the defects that could be affected by the teratogen (etiological homogeneity). It was therefore important to attempt to quantitatively assess the ability to detect changes in birth defect rates and share this information openly with all stakeholders. This open communication helped to characterize the capability of the monitoring system to address citizen concerns and inherent limitations.

Ongoing communications with stakeholders in various formats helped keep this project on course. Examples include the the Rocky Mountain Arsenal Website, “Health Matters” newsletters and multiple presentations at CAB meetings. In addition, CRCSN staff was available by phone to address questions. Varied avenues also allowed the distribution of educational materials such as information about having a healthy pregnancy.

The geographic distribution of birth outcomes is reported to the CRCNS based on the mother's place of residence at the time of birth. It is recognized that births occurring outside the study area, but with some portion of gestation occurring at an alternate address within the study area, would likely be lost to follow-up. In addition, some births may have been included even though residency within the study area was very limited in duration. The CRCNS birth defects surveillance database could be improved if data on maternal residency throughout gestation were collected.

In Colorado, vital record data are available in a timely manner needed for monitoring. Almost complete spatial data are available within a three-month time lag. Similarly, the majority of birth defect data are received within 90 days of diagnosis. This project ran quarterly analyses that utilized all previously and newly reported data for the entire study period, therefore being able to achieve a balance between timeliness and completeness. The data and data sources used for this project are considered the gold standard in coverage and quality for birth occurrence and birth defect data for the entire State of Colorado.

## **References**

Fleiss, JL (1973): *Statistical Methods for Rates and Proportions*. New York, NY: John Wiley and Sons, Inc.

Kulldorf M, Nagarwalla N (1995): *Spatial Disease Clusters: detection and inference*. *Stat Medicine* 14:799-810.

Lucas JM (1985): *Counted data CUSUM's*. *Technometrics* 27:129-144.

## **Appendix A. Colorado Responds to Children with Special Needs**

CRCSN is the birth defects monitoring and prevention program at the Colorado Department of Public Health and Environment. CRCSN started operating in 1989 under the guidance of an advisory board of parents, physicians, advocates and representatives from state agencies.

To be included in CRCSN, a child must be a Colorado resident diagnosed prenatally to age three years with one of the eligible conditions on the listed below. Children meeting these criteria are identified by information from hospitals, vital records (birth, death and fetal death certificates), the Newborn Genetic Screening Program, the Newborn Hearing Screening Program, laboratories, physicians, and genetics, developmental and other specialty clinics. About 5 percent of all births have major congenital anomalies. About 7,000 children or 13 percent of the births in Colorado each year are identified because they meet CRCSN eligibility criteria.

To do its job, monitoring and preventing birth defects, CRCSN gathers and receives information on persons from a variety of data sources such as: doctors, laboratories and hospitals. CRCSN then reviews the relevant portions of this information to develop measures to monitor and prevent the spread of birth defects. Colorado law authorizes our access to these special records, but also requires that we protect their privacy. “Privacy” and “confidentiality” are important values for CRCSN. This is how we protect the privacy of the records and reports in our possession:

- **Physical Security:** The doors to our offices are locked at all times and access is restricted; for some this seems unfriendly, but it’s an important way we maintain the public’s trust
- **Internal Policy:** Every employee is trained in the importance of protecting privacy. Every employee must sign a confidentiality agreement. We have a standard policy on the release of statistical data that prevents the identification of individuals.
- **State Law:** Colorado law provides stronger legal protection for public health reports and records of all reportable conditions than for regular medical records in doctors’ offices or hospitals or records in other parts of the Health Department. That means that the public health records we possess cannot be subpoenaed by courts or shared with other agencies of state government and are not subject to “freedom of information” requests.
- **Criminal Penalties:** Employees who breach the confidentiality of personal medical information may receive fines or jail sentences or both.

# CRCSN Eligibility Criteria

- ✓ Resident of Colorado
- ✓ Diagnosed prenatally to the third birthday
- ✓ Diagnosed as having one of the following conditions

## CONGENITAL ANOMALIES

- Central nervous system
- Cardiovascular
- Circulatory
- Respiratory
- Eye, ear and face
- Orofacial
- Gastrointestinal
- Genitourinary
- Musculoskeletal
- Chromosomal abnormalities
- Congenital anomaly syndromes

## GENETIC, ENDOCRINE AND METABOLIC DISORDERS

- Newborn Genetic Screening Diagnoses
  - Phenylketonuria (PKU)
  - Congenital hypothyroidism
  - Hemoglobinopathies
  - Galactosemia
  - Cystic fibrosis
  - Biotinidase deficiency
  - Congenital adrenal hyperplasia
- Disorders of amino acid transport and metabolism
- Disorders of carbohydrate transport and metabolism
- Lipidoses
  - Disorders of copper metabolism
  - Other disorders of purine and pyrimidine metabolism
- Mucopolysaccharidosis

## ENVIRONMENTAL RISK FACTORS

- Maternal age 15 years or less
- Maternal education less than 12 years and no prenatal visits

## MEDICAL DIAGNOSES AND RISK FACTORS FOR DEVELOPMENTAL DELAY

### Birth Outcomes and Perinatal Conditions

- Birth weight less than 1500 grams
- Prematurity less than 32 weeks gestation
- Small for gestational age
- APGAR 3 or less at 5 minutes
- Meconium aspiration syndrome
- Birth trauma
- Intracranial hemorrhage
- Convulsions/seizures
- Drug withdrawal syndrome in the newborn
- Noxious influences affecting fetus
- Fetal alcohol syndrome
- Congenital perinatal infections

### Sensory, Development and Growth Conditions

- Hearing loss
- Blindness and low vision
- Retinal degeneration
- Speech and motor delays
- Growth and weight delay
- Mental retardation
- Infantile cerebral palsy
- Dystrophy: muscular and spinal
- Degenerative CNS/Cerebral lipidoses

### Other Risk Factors for Developmental Delay

- Encephalitis
- Meningitis
- Injury: head and spinal cord
- Cerebral cysts
- Child maltreatment syndrome
- Chorioretinitis
- Infantile spasms
- Renal tubular acidosis

## Appendix B. Maternal Demographics of Births in the RMA Study Area: 1989-1996

The following four figures provide information on the demographic variables of age, race, education and marital status of mothers at time of birth for residents of the RMA study area and the State of Colorado as a whole.

Figure 1. Age of Mother: RMA Study Area Residents vs Colorado Residents 1989-1996

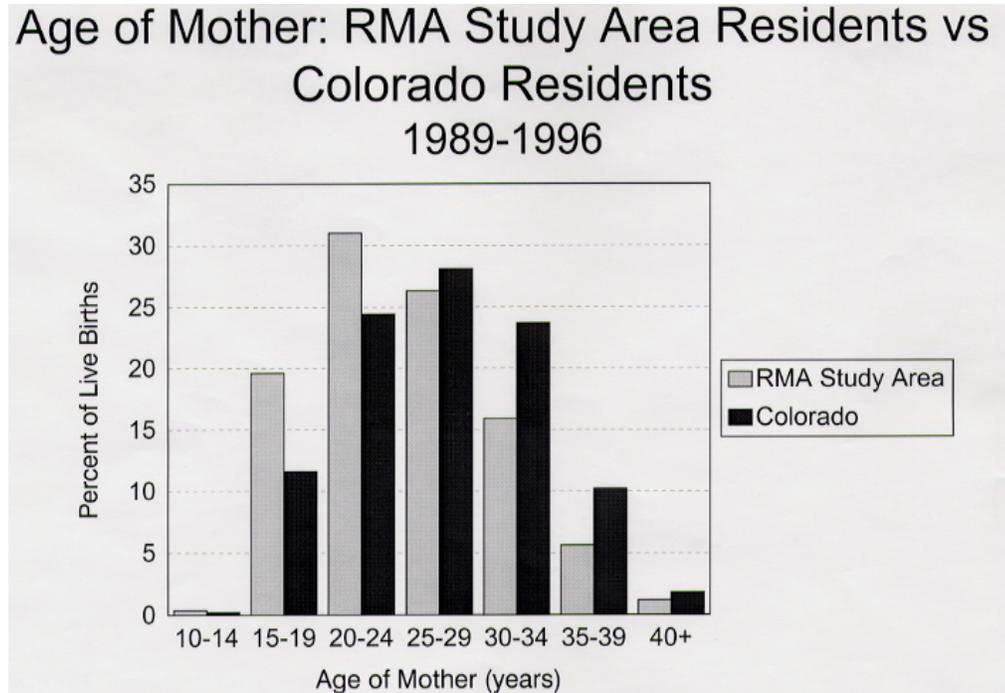


Figure 2: Race/Ethnicity of Mother: RMA Study Area Residents vs Colorado Residents 1989 – 1996

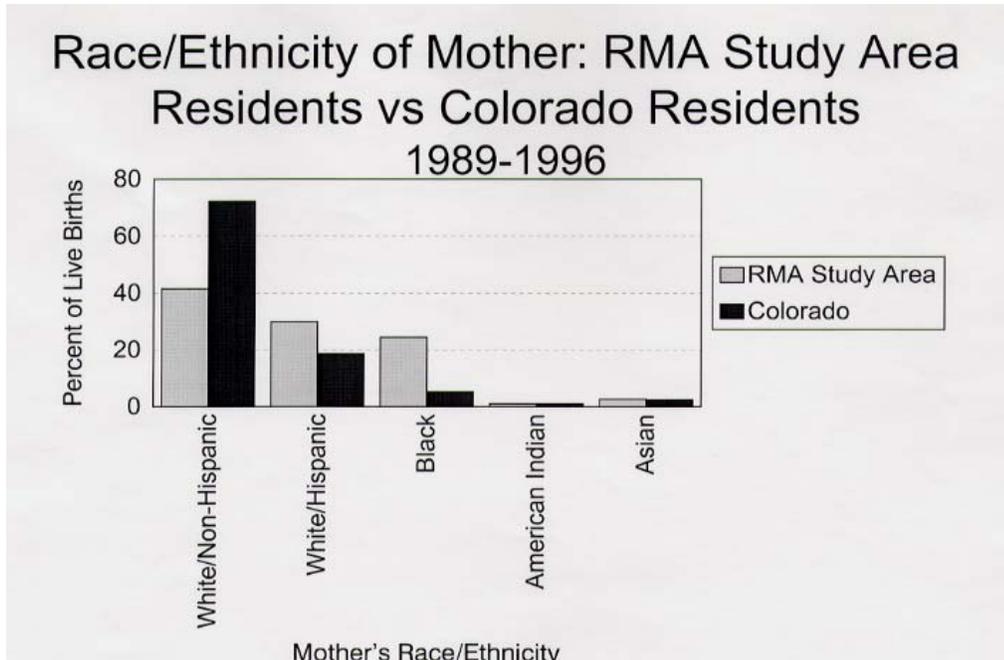


Figure 3: Education of Mother: RMA Study Area Residents vs Colorado Residents 1989 - 1996

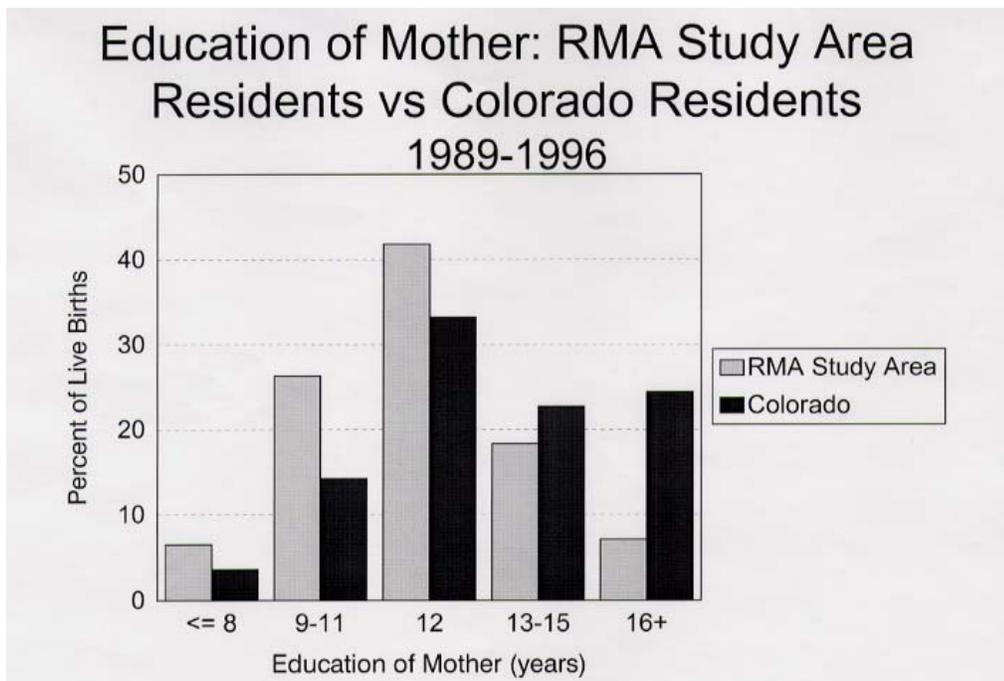
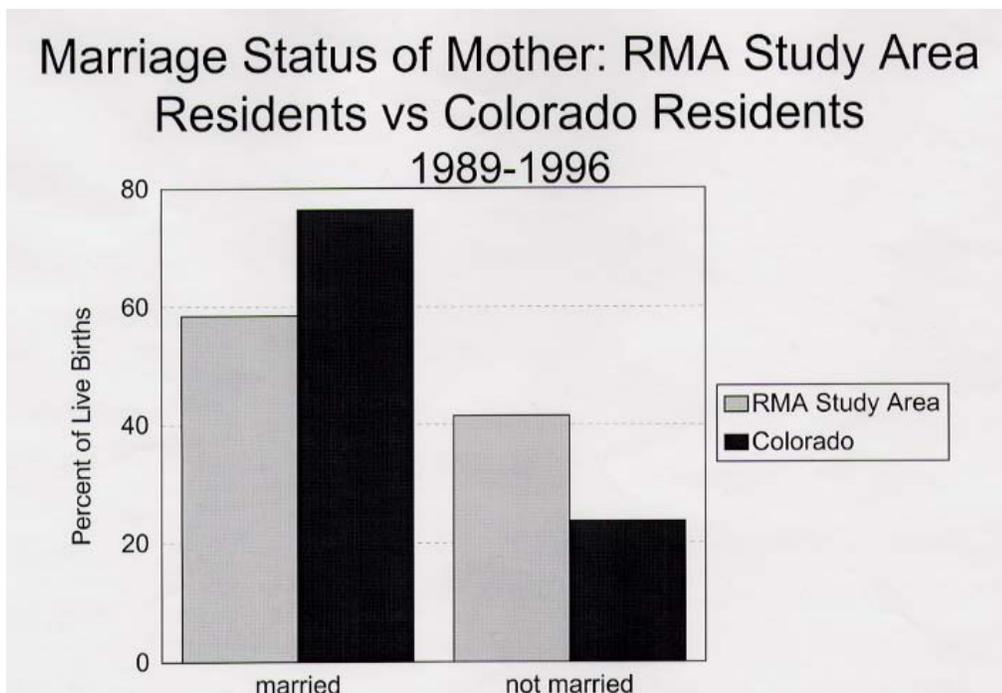


Figure 4: Marriage Status of Mother: RMA Study Area Residents vs Colorado Residents 1989 – 1996



It is important to consider the demographics of women giving birth in any analysis of birth defects rates. Historically, on a nationwide level, it has been observed that rates of birth defects vary across racial and social economic groups, and differ based on the age distribution of the mothers' living in an area. Although the definitive causes for these differences have not been completely defined, examining demographic factors can help us understand what we might expect to see occurring in an area. For example, birth defects occur more often in older and very young mothers.