



MARK B HORTON, MD, MSPH
Director

State of California—Health and Human Services Agency
California Department of Public Health



ARNOLD SCHWARZENEGGER
Governor

Dear Health Care Provider:

California State law (Title 17, California Code of Regulations, Section 6531 & 6532) requires that neural tube defects (NTDs) and/or chromosomal abnormalities found in fetuses or infants less than one year of age be reported to the California Genetic Disease Screening Program (GDSP). Enclosed we have provided the latest Confidential Case Report of a Birth Defect forms (CCR) for this reporting. You may also obtain additional forms in pdf format from our website: http://cdph.ca.gov/GDSP/Pages/PDE_Downloadable_Documents.aspx. The forms can be emailed to our office utilizing secure encryption. If you are unable to provide information requested on the form, please be sure to list any other source where we might obtain such information.

The State CCR forms are designed for reporting NTDs and Chromosomal abnormalities. Cytogenetic laboratories may report chromosome abnormalities by completing Section A: Boxes 47-55 however, if your hospital refers specimens for testing to a cytogenetic laboratory located outside of the State of California, it is the responsibility of the referring laboratory to complete the CCR form and submit it to our offices. Non-laboratory departments reporting chromosomal abnormalities **need not** complete the CCR form. A computer printout using **ICD 9CM Codes 758.0 - 758.9** will be accepted. The report must include: Mother's name and date of birth, infant's name, date of birth and gender, name of the cytogenetic laboratory performing the test and cytogenetic lab specimen number, if available. An example of the format and a PDF fill-able form has been developed and included in this mailing for your convenience.

Neural Tube Defects (**ICD 9CM codes 740.0-742.0**) must be reported on a completed CCR form in Section B. In reportable cases where both abnormalities may exist, please record the information for both abnormalities on the CCR form. We may occasionally need to contact you for additional information on a particular case.

The data your facility provides are vital for evaluating the effectiveness of the California Expanded AFP Screening Program and for monitoring the geographical and ethnic distribution of birth defects (NTDs and chromosomal abnormalities) throughout the state. These data also allow genetic counselors to calculate a woman's risk of having a child with a birth defect. It is mandated that these data be submitted within 30 days of diagnosis, but many facilities find it more practical to send forms quarterly. We are providing a Quarterly Tracking of Birth Defects form for you to submit along with your completed CCRs. This form is PDF online fill-able. If there were no cases for the reporting quarter you may place an "X" using the spacebar on your keyboard in Box number 15 and return the form by email. Hopefully, this method of reporting will reduce the workload for your facility.

Please know that HIPAA does not affect this reporting requirement. Health care providers may provide personal health information for public health surveillance and operations.

Please mail your completed forms to Marie Roberson at the address below. You may also fax your forms to: (510) 412-1560. If you have any questions or concerns, please contact Marie Roberson at (510) 412-1522 or Marie.Roberson@CDPH.ca.gov

Thank you for your continued support and cooperation in this effort.

Sincerely,

Fred Lorey, Ph.D.
Acting Chief, Genetic Disease Screening Program