



***Ad-hoc* Meeting of Experts to Establish Best Practices in CRS Surveillance**

During the XVI Meeting of the Technical Advisory Group (TAG) on Vaccine-preventable Diseases in November 2004, recommendations were made to enhance the progress already achieved in the Region toward the goal of rubella and congenital rubella syndrome (CRS) elimination. One principal recommendation was the proposal for PAHO to convene an *ad-hoc* meeting of experts to define good public health practices for establishing CRS surveillance.

The rubella and CRS elimination strategies implemented in the Americas have resulted in substantial progress to date. As countries of the Region progress towards elimination, new challenges for the detection of suspected CRS cases have become evident. Quality of rubella and CRS surveillance remains a key challenge.

The *Ad-hoc* Meeting of Experts to Establish Best Practices in CRS Surveillance was held in Washington, D.C., on 10-11 July 2006. Experts from Argentina, Australia, Brazil, Canada, Costa Rica, Ecuador, India, Mexico, Nicaragua, Peru, the United Kingdom, the United States, and Venezuela presented lessons learned from their experiences. Professionals in areas of ophthalmology, cardiology and audiology shared their experiences in working with CRS-affected children.

The goal of the meeting was to develop best practices for the detection and surveillance of suspect CRS cases in the Region. Meeting participants shared experiences and lessons learned in order to generate recommendations for enhanced detection and improved surveillance of suspect CRS cases. They upgraded the existing guidelines to be disseminated to public health workers, and also identified opportunities to increase awareness among physicians and other health workers regarding CRS detection.

The following table summarizes the final conclusions and recommendations of the meeting.

Topics	Conclusions and Recommendations
Goals of CRS surveillance	<p>The main goals of CRS surveillance should include:</p> <ol style="list-style-type: none"> Monitoring trends; Assessing the impact of immunization programs; Identifying reservoirs of transmission; Helping to develop or modify program policy, if appropriate; Verifying the interruption of endemic transmission of rubella virus in the Americas, including identification of imported cases; and Serving as a critical advocacy tool.
Defects and key findings in a neonate or infant that should alert a physician to a suspect CRS case	<ul style="list-style-type: none"> Hearing impairment is the most common defect, followed by cardiac and eye defects. Key findings that may alert a physician include: <ol style="list-style-type: none"> Suspicion of hearing impairment by simple observational testing; Sweating, palpitations, rapid heart beat, and changes of skin color for cardiac problems; and Absence of red eye reflex.
Sensitivity and quality of CRS surveillance	<ul style="list-style-type: none"> A sensitive case definition should be implemented by using key findings/signals that can be detected at the primary care level. Clinical guidelines and practical tools should be developed for use at the primary care level to improve detection of signals/alerts for hearing impairment, cardiovascular problems, and eye defects. Awareness of health workers, health students, communities, and families should be increased through training. Sentinel site reporting – including secondary and tertiary hospitals, specialty clinics, specialists, and the use of TORCH¹ as a differential diagnosis – should be strengthened. Serological and virological laboratory testing of all suspect CRS cases should be encouraged. Partnerships with specialists should be built and interprogrammatic coordination strengthened. Quality and flow of information should be maintained through staff training and feedback to all levels of health services.
Role of routine screening for certain defects such as hearing impairment or red eye reflex	<ul style="list-style-type: none"> Because of limited resources, many countries will not be able to use OAEs² or ABRs³. These countries may want to explore the use of simple observational hearing tests. Routine screening of major defects can lead to early treatment and intervention. This is particularly important for infants with hearing impairment. Routine auscultation of the heart can assist in the diagnosis of congenital heart defects. A majority of cataracts can be identified by using simple techniques such as red reflex.
CRS awareness among physicians and other health workers in hospitals and primary care settings for detecting suspect CRS cases in their patient	<ul style="list-style-type: none"> Health workers, including students in health careers, should be trained on CRS signs and clinical findings. Health promoters, midwives, families, and communities should be trained on how to detect CRS signals/alerts. A training plan for health workers to increase awareness about the clinical, laboratory, and epidemiologic aspects of rubella and CRS should be developed.

¹ TORCHS stands for Toxoplasma gondii; other viruses (HIV and more); rubella (German measles); cytomegalovirus; herpes simplex; and syphilis.

² Otoacoustic emissions testing.

³ Auditory brainstem response.

populations	<ul style="list-style-type: none"> • Training materials must be designed with the participation of different health programs. New educational technology such as long distance learning and “virtual public health campus” can be used.
Systems that can be used to identify CRS cases	<p>CRS cases can also be identified by:</p> <ol style="list-style-type: none"> a) Reviewing birth defects registers such the National Congenital Malformation Registers and ECLAMC⁴ for compatible signs and symptoms; and b) Strengthening the interprogrammatic use of information from sources such as the Perinatal Information Systems of CLAP/WR⁵, and national databases related to child and maternal health.
Role of the laboratory in CRS surveillance in the context of rubella and CRS elimination	<ul style="list-style-type: none"> • Laboratory confirmation of cases is critical. • The collection of specimens for viral isolation is necessary to understand the molecular epidemiology and differentiate between endemic transmission and imported cases. • The coordination between epidemiologist and the laboratory is critical. Both groups should actively participate in activities pertaining to the surveillance system.
Rubella IgM in a pregnant woman	<ul style="list-style-type: none"> • IgM should be obtained ONLY when there is a history of rash or contact with a rubella-like rash. IgM is NOT recommended for routine antenatal testing.
Activities to be coordinated between the epidemiology and laboratory groups	<ul style="list-style-type: none"> • A practical guide should be developed for specimen collection, description, and indication for use, and interpretation of laboratory tests and results. • Appropriate training material should be developed, including topics such as clinical manifestations, epidemiology, and laboratory. • A group of national experts should be formed that would meet regularly to examine the current epidemiology, evaluate the status of the vaccination program, and address unresolved issues.
Coordination of rubella and CRS activities	<ul style="list-style-type: none"> • Rubella and CRS surveillance activities should be coordinated at all levels of the health care system. • Proper CRS case follow-up (including diagnosis, treatment, and classification) should be ensured by designating a surveillance coordinator. • The use of the information system supported by PAHO should help to ensure consistency and opportunity of data collection and analysis. • A multidisciplinary team should be established to evaluate and classify suspect rubella and CRS cases and regularly assess the adequacy of the surveillance system.
Role of non-physicians such as audiologists and personnel from schools for the deaf and/or blind	<ul style="list-style-type: none"> • Inclusion of personnel caring for deaf and/or blind children and adults is important when setting up a CRS surveillance system. • Personnel can be included as part of the multidisciplinary teams and networks to disseminate and share information.
Role of professional societies	<ul style="list-style-type: none"> • There should be a strong partnership between public health institutions and professional societies in all countries. • CRS surveillance can be promoted through congresses, conferences, web pages, bulletins, and journals of these societies.
Evaluation and monitoring of CRS surveillance for completeness of	<p>Three aspects of the system need to be evaluated periodically:</p> <ol style="list-style-type: none"> a) Completeness of CRS reporting. This may include retrospective searches in secondary and tertiary hospitals and schools for the deaf or blind;

⁴ ECLAMC: Spanish acronym for the Latin American Collaborative Study on Congenital Malformations.

⁵ CLAP/WR: Spanish acronym for the Latin American Center for Perinatology, Women and Reproductive Health.

reporting and verification of rubella and CRS elimination	<ul style="list-style-type: none"> b) Functionality and efficiency of the system at the peripheral and national levels; and c) Evaluation of quality and completeness of data, specimen collection, and transportation.
Mechanisms for sharing and disseminating information	<ul style="list-style-type: none"> • Networks that include physician groups, professional and academic societies, and NGOs should be formed. • PAHO should assist with these CRS information dissemination efforts.