VaCARES Reporting Manual for Users

VA♥CARES

VIRGINIA GENETICS PROGRAM

Virginia Congenital Anomalies Reporting and Education System (VaCARES)
Virginia Department of Health
September 2002

VaCARES Reporting Manual for Users

A user manual on reporting birth defect data to VDH using the Virginia Infant Screening and Infant Tracking System (VISITS).

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I. General Information

VaCARES

Birth Defect Registry. The Virginia Congenital Anomalies Reporting and Education System (VaCARES) is a statewide population-based birth defect registry covering about 95,000 children born in Virginia each year.

VISITS

New Reporting System. The Virginia Infant Screening and Infant Tracking System (VISITS) is an integrated database system that tracks screening results for several program and services administered by the Virginia Department of Health (VDH), including VaCARES. The VISITS database replaces the VaCARES paper forms previously submitted on a monthly basis to VDH. Hospitals now have the opportunity to enter a birth defect diagnosis directly into the VISITS database. It is recommended that the hospital user enter data on a regular basis, at a minimum of once a month.

Starting Date. Hospitals that report birth defect data to VDH are to use the VISITS database to report children with a diagnosis of a birth defect effective on the date that VISITS goes on-line, which is on or around September 9, 2002. VISITS-VaCARES updates are available on the VISITS Public Web page www.visits.org.

Browser Requirements. VISITS is a Web application. In order to view the application properly, you should use Microsoft Internet Explorer 6.0 browser or higher when data into the VISITS database.

User Prerequisites. All users should have available a copy of the *VISITS-VaCARES Training Manual*, which is available online from the VISITS Public Web page www.visits.org, and have participated in a Webex training session prior to using the system for the first time. Before using the VISITS-VaCARES application, all users must:
1. Read the VISITS security guidelines, entitled *Information Systems: Security and Confidentiality Policies, Procedures, and Standards*, Virginia Department of Health.
2. Sign and return the following forms, which are in the above VISITS security guidelines, to VDH:
   a. Certificate of Receipt (of VISITS security guidelines).
   b. Information Systems Security Access Agreement: VISITS.
3. Participate in a training session for VISITS users.

II. Legislated Screening Requirement

Beginning of VaCARES. In 1985, the General Assembly of Virginia passed legislation creating the Virginia Congenital Anomalies Reporting and Education System and mandating the collection of birth defect data. The VaCARES reporting system began in January 1987.

Goals. VaCARES has three specific goals:
1. To collect data to evaluate the possible causes of congenital anomalies.
2. To improve the diagnosis and treatment of birth defects.
3. To establish a mechanism for informing the parents of children identified as having birth defects and their physicians about available health resources.

Hospital Requirement. The *Code of Virginia* § 32.1-69.1 states, in part, "The chief administrative officer of every hospital, as defined in § 32.1-123, shall make or cause to be made a report to the [State Health] Commissioner of any person under two years of age diagnosed as having a congenital anomaly."

Prior to the creation of VaCARES, it was not known with certainty how many infants were born in Virginia with anomalies or how many children were in need of services. From epidemiologic research, it had been estimated that three percent of newborns have an identifiable major congenital anomaly. However, some anomalies are not readily detected at birth resulting in under-reporting of congenital anomalies on birth certificates. This prevented a precise understanding of the scope of the problem in our population. VaCARES has helped Virginia close that gap through the identification of affected children from hospital reports.

Confidentiality. The *Code of Virginia* § 32.1-69.2 states, "The [State Health] Commissioner and all other persons to whom data is submitted pursuant to § 32.1-69.1 shall keep such information confidential. No publication of information shall be made except in the form of statistical or other studies which do not identify individuals. However, the Commissioner may contact the parents of children identified as having birth defects and their physicians to collect relevant data and to provide them with information about available public and private health care resources."

Code of Virginia. For all legislation pertaining to VaCARES, please see Appendix A.

> **Note:** Although this manual reflects the most up-to-date legislation at the time of publication, users of *VaCARES Reporting Manual for Users* are advised to confirm state laws relating to VaCARES.

III. Congenital Anomaly

Definition. VaCARES defines a congenital anomaly as serious structural, functional, or biochemical abnormality due to genetic or environmental factors or both, that is present at birth even though it may not be manifested until later in life. The abnormalities to be reported consist of those ICD-9-CM codes listed in Table 1.

> **Note:** Although VISITS will accept all ICD-9-CM Codes, hospitals only need to enter those ICD-9-CM codes that are listed on the VaCARES ICD Code List.

Table 1. VaCARES ICD Code List

List of ICD-9-CM Codes for VaCARES	
ICD-9-CM code range	Description
042	HIV
090	Congenital syphilis
189-191, 237-239	Congenital Malignant Neoplasms, Congenital Neoplasms
240-259	Endocrine disorders
270-277, 279	Metabolic and immune disorders
282, 284, 286	Specified anemias and coagulation defects
330-343, 352-359	Nervous system disorders
362-363	Retinal disorders
369	Blindness
389	Hearing loss
425-427	Cardiomyopathy and conduction disorders (exclude 427.5 - cardiac arrest)
524	Dentofacial anomalies
740-759	Congenital anomalies
760.7	Noxious influences affecting fetus via placenta or breast milk
771.0-771.2	Selected congenital infections

IV. Instructions for Completion of VISITS-VaCARES Reports

Required Information. The quality of the congenital anomaly data in Virginia relies on receiving useful, accurately completed VaCARES Reports. Please complete to the best of your ability all the information required in the database. If any of the items are not in your records, enter "U" (unknown) in the appropriate space. Do not leave any space blank**. *You will not be allowed to save the entry if you leave fields empty.***

Age of Child. Complete a VaCARES Report for each and every admission of all newborns and children who are under 2 years of age (i.e., under 24 months old) when admitted to the hospital and who have at least one VaCARES diagnosis code. The VaCARES diagnosis code can be any code in any range in the previous ICD-9 CM Codes for VaCARES. *Complete a VaCARES Report even if the child died.*

Frequency of Reports. Please enter reports for children discharged on or after the first day of the month no later than the 15th of the subsequent calendar month. Frequent submission of reports facilitates the educational aspects of the program.

Post Cards. Until further notice, the postage-paid postcards for reporting that no child was discharged with a diagnosis from the VaCARES code list during a given month will continue to be available. These postcards also must be returned by the 15th of the subsequent calendar month. Please make sure that the correct hospital code is included. Postcards may be obtained from:

> VaCARES
> Virginia Department of Health
> Division of Child and Adolescent Health, Room 136
> P.O. Box 2448
> 1500 East Main Street
> Richmond, Virginia 23218-2448
> Phone: 804-225-4035

V. Entering Data Into VISITS-VaCARES Database

Introduction

Required Data Fields. The following section includes instructions for completing each item on the VISITS-VaCARES screens. Items in **red** are required information and must be entered in order to move on to the next item. Enter "U" (unknown) for any items that are not in your records. Please pay careful attention to spelling of names and entering the correct date of birth, death, etc.

Hospital Access to VISITS Data. To ensure the security of the system, hospitals will only have (review) access to the data they originally entered into the database.

VISITS-VaCARES Training Manual. Please refer to the *VISITS-VaCARES Training*

Manual For Users for specific information about using the database.

A. Infant Data Screen

See <u>Figure A. Infant Data Screen</u>.

<u>Client's SSN</u> – If known, enter child's social security number.

<u>Client Control #</u> - This is an automatically populated field.

<u>Birth Medical Record #</u> - Enter the child's medical record number as assigned by your hospital.

<u>Birth Certificate #</u> - If known, enter number.

<u>Birth Hospital</u> - Click drop-down box and click the appropriate hospital.

<u>Date of Birth (DOB)</u> - Click field and pop-up calendar will appear. Click the appropriate date and field will populate.

<u>Order of Births</u> - Type in the child's placement in the order of birth. If a single birth, enter "1"; if the second of twins, enter "2"; etc.

<u>Death Certificate</u> - If child is deceased and death certificate number is known, populate the field with the number on the death certificate.

<u>Date of Death</u> - If child is deceased, click field and pop-up calendar will appear. Click the appropriate date and field will populate.

<u>First Name</u> - If child's name is known, populate the field with name. If child was not named, identify as either "BB" or "BG".

<u>Middle Name</u> - If child's name is known, populate the field with the name.

<u>Last Name</u> - Enter the child's surname in the field.

<u>Gender</u> - Use drop-down box to enter child's sex in this field.

<u>Race</u> - Click the drop-down box and select from the options listed.

<u>Ethnicity</u> - Click the drop-down box and select from the options listed.

<u>Mother is Primary Contact</u> - Check the box if this is true.

<u>Mother's First Name</u> - Enter mother's first name.

Mother's Last Name - Enter mother's last name.

Mother's SSN – If known, enter mother's social security number. If unknown, enter "unknown" in the field.

Mother's Maiden Name - If known, enter mother's maiden name. If unknown, enter "unknown". If same last name, enter "same".

Father's First Name - Enter father's first name.

Father's Last Name - Enter father's last name.

Children in household – If known, enter number. If unknown, enter "unknown".

Adults in household – If known, enter number. If unknown, enter "unknown".

Primary Physician - Search box will pop up. Enter doctor's last name and search the list that appears for the correct physician.

Figure A. Infant Data Screen

B. Family Contact Data

See

Primary Contact/Relation to Client - This is a required field—click drop-down box to select appropriate relationship to child.
- If primary contact is the child's mother, the first and last name boxes will automatically populated. Otherwise, type in the first and last name of the primary contact for the child.

Primary Language Spoken - Use drop-down box to populate this field.
- This is a required field. Make all reasonable attempts to provide correct information.

Address - Type in the complete address, including street address, city, state, and zip code.

Figure B. Family/Contact Data Screen

C. Birth Defect Registry

See <u>Figure C. Birth Defect Registry Screen</u>.

<u>Registry Type</u> – This is an automatically populated field.

<u>Medical Records Number</u> - This is a required field.

<u>Registry Hospital</u> - Click drop-down box and click the appropriate hospital.

<u>Registry Setting</u> - This field is required and is automatically populated.

<u>Person Entering Registry</u> - This is a required field and is automatically populated.

<u>Was Child Transferred to Another Hospital</u> - This is a required field with drop-down options of "Yes" or "No".
- If "Yes", then "Hospital Transferred To" is required although it is not printed in red.

<u>Is Child Deceased?</u> - This is a required field with drop-down options of "Yes" or "No".
- If "Yes", then "Date of Death" and "Cause of Death" are required fields. The "Cause of Death" field will be a text field. Type in the primary cause of death as indicated on the discharge summary, death certificate, etc.

<u>Date of Admission</u> - Click field and pop-up calendar will appear. Click the appropriate date and field will populate. This is a required field.

<u>Date of Discharge/Transfer</u> - Click field and pop-up calendar will appear. Click the appropriate date and field will populate. This is a required field.

<u>Attending Physician</u> - This is a required field. Type in the name of the doctor who was the child's primary physician during hospitalization.

<u>Physician Discharged To</u> - This is a required field. Type in the name of the doctor who will provide follow-up care for the child.

<u>Vietnam Service</u> - This information is not required but is helpful if available.

<u>Diagnosis Code</u> - This is a required field. Click in the field to enter the code for the infant's birth defect. The complete code is required (e.g., 493.91). After you enter the code, click in or tab to the Description field—the description will automatically appear.
- Proceed to the Status field and click the drop-down box to enter the diagnosis as, "Confirmed", "Provisional" or "Unknown".

Figure C. Birth Defect Registry Screen

Birth Defect Registry

VISITS Registry Details for: **Matchull Testford: 3067515**

Registry Type	Birth Defect	Date Registry Form Completed	
Medical Record Number	1111111		
Registry Hospital	CHIPPENHAM MEDICAL CENTER		
Screening Setting	Hospital (Outpatient)		
Person Entering Registry Information	Joan Corgiei		
Was this Child Transferred:	No		
Hospital Transferred To			

Is this Child Deceased	No		
Cause of Death		Date of Death	
Date of Admission		Date Discharge/Transfer	
27-AUG-2002		29-AUG-2002	
Select Attending Physician		Select Physician Discharged To	
Brown, Susan		Brown, Susan	

Parent Vietnam Service	Parent Length of Service in Vietnam		Parent Exposed to Agent Orange
	to		

Registry Entry Date	28-AUG-02	Created By	NANCY FORD	Date Registry Form Received	

Source: Hospital

Diagnosis Code	Description	Status
758.0	DOWN'S SYNDROME	Provisional

Case Status Details

Case Status:	
Status Date:	
Status Comments:	

[Save Screening] [Cancel Screening]

If you have questions about VaCARES or about the use of the VISITS/VaCARES database contact:

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Appendix A. Code of Virginia Citations

Note: Users of the manual are advised to consult the most recent edition of the *Code of Virginia* to make sure that the following Codes are up to date.

§ 32.1-69.1. Virginia Congenital Anomalies Reporting and Education System.

A. In order to collect data to evaluate the possible causes of birth defects, improve the diagnosis and treatment of birth defects and establish a mechanism for informing the parents of children identified as having birth defects and their physicians about the health resources available to aid such children, the Commissioner shall establish and maintain a Virginia Congenital Anomalies Reporting and Education System using data from birth certificates filed with the State Registrar of Vital Records and data obtained from hospital medical records. The chief administrative officer of every hospital, as defined in § 32.1-123, shall make or cause to be made a report to the Commissioner of any person under two years of age diagnosed as having a congenital anomaly. This report shall include information on the parent's service in Vietnam, the duration of the service and possible exposure to Agent Orange through its development, testing or use. The Commissioner may appoint an advisory committee to assist in the design and implementation of this reporting and education system with representation from relevant groups including, but not limited to, physicians, geneticists, personnel of appropriate state agencies, persons with disabilities and the parents of children with disabilities.

B. With the assistance of the advisory committee, the Board shall promulgate such regulations as may be necessary to implement this reporting and education system. These regulations may include determinations of specific genetic disorders to be monitored, the scope of the information to be collected, appropriate mechanisms for follow-up, relationships between the reporting and education system and other agencies and mechanisms for review and evaluation of the activities of the system. The reporting and education system may collect the name, address, sex, race, and any other information, determined to be pertinent by the Board, regarding persons reported to have birth defects. (1985, c. 273; 1986, c. 136; 1988, cc. 459, 843; 1994, c. 854.)

§ 32.1-69.2. Confidentiality of records; publication; authority of Commissioner to contact parents and physicians.

The Commissioner and all other persons to whom data is submitted pursuant to § 32.1-69.1 shall keep such information confidential. No publication of information shall be made except in the form of statistical or other studies which do not identify individuals. However, the Commissioner may contact the parents of children identified as having birth defects and their physicians to collect relevant data and to provide them with information about available public and private health care resources. (1985, c. 273.)