

**DEPARTMENT OF HUMAN SERVICES, PUBLIC HEALTH DIVISION  
CHAPTER 333**

**DIVISION 10  
HEALTH PROMOTION AND CHRONIC DISEASE  
PREVENTION**

**Childhood Diabetes Database**

**333-010-0600**

**Definitions**

- (1) "Case" means a reportable case of type 1 or type 2 diabetes in an individual who is 18 years of age or younger, and a resident of Oregon.
- (2) "Diabetes Program" means the Oregon Diabetes Prevention and Control Program of the Department of Human Services, Public Health Division, the program authorized to collect, receive, and maintain a childhood diabetes database under ORS 444.300.
- (3) "Date of diagnosis" means the date of initial diagnosis by a practitioner of a case of diabetes being reported to the Diabetes Program.
- (4) "Effective Date" means the date after which reporting by schools and physicians shall be required.
- (5) "Identifying information" includes, but is not limited to the student's name, address, date of birth, and information that identifies the individual or could be used to identify the individual, and relates to the individual's past, present or future health, and the provision of healthcare to the individual. "Identifying information" also includes "Individually Identifiable Health Information" as that is defined in the 1996 Health Insurance Portability and Accountability Act and "Directory Information" as that is defined in the Federal Family Educational Right to Privacy Act (FERPA) (20 U.S.C. § 1232g; 34 CFR Part 99).
- (6) "Practitioner" means any person whose professional license allows him or her to diagnose or treat diabetes patients.
- (7) "Reportable childhood diabetes" means a medical condition, occurring in a person aged 18 years or younger, and meeting the criteria for diagnosis of diabetes in a child as outlined by the American Diabetes Association. (Reference: American Diabetes Association. Standards of Medical Care in Diabetes. Diabetes Care 2005; 28 [Supplement 1]: S4-S36.)
- (8) "School" means any public, public charter, or registered private school in Oregon.

Stat. Auth.: 444.300

Stats. Implemented: 444.300-ORS 444.330

### **333-010-0610**

#### **General Authority and Purpose**

According to ORS 444.300(1), subject to available funding, including gifts, grants or donations, the Diabetes Program shall establish a uniform, statewide database for the collection of information on type 1 and type 2 diabetes occurring in children in Oregon. The purposes of the database shall be to collect and serve as a repository for data about the prevalence and incidence of diabetes occurring in the pediatric population of this state and to make the data available for scientific and medical research and for assistance in making decisions about the allocation of public resources.

Stat. Auth.: ORS 444.300

Stats. Implemented: ORS 444.300 – ORS 444.330

### **333-010-0620**

#### **Reporting Requirements for Schools**

(1) The Diabetes Program shall conduct an annual survey to collect information about diabetes occurring in students age 18 years or younger. Preferably the survey will be completed and returned to the Diabetes Program within 30 days of the date the survey or electronic survey link is sent out, but in no event, later than June 15 of each year.

(2) Each school surveyed, upon receipt of written consent of the parent, guardian (or of the student if age 18 years) shall report to the Diabetes Program for each student enrolled at the school, during the academic year, who has type 1 or type 2 diabetes, the following information:

- (a) The name and address of the student;
- (b) The sex of the student;
- (c) The date of birth of the student;
- (d) The type of diabetes diagnosed (if known);
- (e) The date of diagnosis; (if known); and
- (f) The name of the child's practitioner (if known).

Stat. Auth.: ORS 444.300

Stats. Implemented: ORS 444.300-ORS 444.330

### **333-010-0630**

#### **Reporting Requirements for Practitioners**

(1) Upon diagnosing or first treating a case of type 1 or type 2 diabetes in an Oregon child, a practitioner shall report the following information to the Diabetes Program:

- (a) The name and address of the child;

- (b) The sex of the child;
- (c) The date of birth of the child;
- (d) The type of diabetes diagnosed;
- (e) The date of diagnosis or first treatment by the reporting practitioner; and
- (f) The measured height and weight of the child.

(2) The practitioner shall report the case to the Diabetes Program within 30 days of diagnosing or first treating the child.

(a) The practitioner shall report the case using the Diabetes Program's Practitioner Childhood Diabetes Report Form. The report may be sent to the Diabetes Program by mail, electronically, or by fax. Copies of the form, and directions for submission may be obtained from the Diabetes Program, 800 NE Oregon Street, Portland, Oregon 97232; or may be downloaded through the Diabetes Program's website.

(b) The Diabetes Program may elect to supplement passive reporting from practitioners with active solicitation of reporting through periodic contacts with certain practitioners.

Stat. Auth.: ORS 444.300

Stats. Implemented: ORS 444.300- ORS 444.330

### **333-010-0640**

#### **Confidentiality and Access to Data**

(1) All identifying information regarding individual patients, reporting schools, and practitioners reported pursuant to OAR 333-010-0620 and 333-010-0630 shall be confidential and privileged. Except as required in connection with the administration or enforcement of public health laws or rules, no public health official, employee or agent shall be examined in an administrative or judicial proceeding as to the existence or contents of data collected under the childhood diabetes database.

(2) The information collected and maintained by the diabetes database shall be stored in physically secure locations and in a technologically secure manner, and shall be used solely for the purposes stated in ORS 444.330

Stat. Auth.: ORS 444.300

Stats. Implemented: ORS 444.300- ORS 444.330

### **333-010-0650**

#### **Research Studies**

(1) Prior to any confidential data from the database being released to a researcher, the researcher must:

(a) Obtain approval from the Department of Human Services, Public Health Division Institutional Review Board, established in accordance with 45 C.F.R. 46.

(b) Obtain approval from the Diabetes Program.

(2) In reviewing research proposals for approval under section (1)(b) of this rule, the Diabetes Program, with input from its advisory committee, shall consider whether the research will:

(a) Further knowledge of the prevalence and incidence of diabetes occurring in the pediatric population;

(b) Better define causes of and treatment for childhood diabetes; or

(c) Inform decision-making about the allocation of public resources.

(3) The Diabetes Program shall also ensure that the research proposal has been reviewed for scientific excellence by a nationally recognized peer review group.

(4) Prior to confidential information being released to a researcher, the Diabetes Program will contact the family and offer the option to decline contact regarding research opportunities.

Stat. Auth.: ORS 444.300

Stats. Implemented: ORS 444.300- ORS 444.330

### **333-010-0660**

#### **Advisory Committee**

(1) The Diabetes Program may convene an advisory committee to make recommendations regarding the Diabetes Program's use of the database, and to assist in reviewing research proposals under OAR 333-010-0650.

(2) Advisory committee members may not have access to confidential information provided to the program under ORS 444.300 to 444.320.

(3) The advisory committee shall be composed of persons with a professional or personal interest in childhood diabetes.

Stat. Auth.: ORS 444.300

Stats. Implemented: ORS 444.300- ORS 444.330