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Evaluation of Type 1 Diabetes among Children and Adolescents in Weston, Wellesley, and Newton

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QUESTIONS AND ANSWERS

1. Why did the Massachusetts Department of Public Health (MDPH) conduct an evaluation of type 1 diabetes among children and adolescents in the communities of Weston, Wellesley, and Newton?

In February 2008, a Weston resident (Ms. Ann Marie Kreft) contacted the Massachusetts Department of Public Health (MDPH) Associate Commissioner and Director of the Bureau of Environmental Health (BEH) to report concerns regarding what she perceived to be an unusual number of children with a diagnosis of type 1 diabetes in the communities of Weston, Wellesley and Newton. The primary concerns focused on children with type 1 diabetes that lived within a few miles of each other in an area where Weston, Wellesley and Newton are contiguous. Additional concerns focused on the possible relationship to environmental exposure opportunities in those communities.

2. What did this evaluation consist of?

To evaluate whether a cluster of type 1 diabetes might exist, it was necessary to first identify all children ages 0-19 years from Weston, Wellesley or Newton with type 1 diabetes to determine the prevalence of the disease in the three communities. Massachusetts is the only state in the U.S. that collects diabetes surveillance data for all children in grades K-8 through its Environmental Public Health Tracking (EPHT) program. However, children less than 5 and older than 14 years of age were among those reported with a diagnosis of type 1 diabetes by Ms. Kreft, so it was necessary to expand surveillance efforts.

3. How did MDPH obtain additional information on children/adolescents 0-19 years of age?

MDPH took a two-phased approach to identify the children and adolescents living in the three communities with a diagnosis of type 1 diabetes. The first effort involved MDPH contacting the public school nurse leaders and private school nurses or administrators in the three

communities to ask them to facilitate the mailing of a letter and consent form to the parents/guardians of children with type 1 diabetes. The second approach was to contact hospitals and endocrinologists in the area to provide MDPH with information on the number of children ages 0 through 19 who they treat from the three communities. MDPH collaborated with Dr. Lori Laffel, Chief of the Pediatric, Adolescent and Young Adult Section at the Joslin Diabetes Center, to design and coordinate data collection and study activities.

4. Why did MDPH ask school nurse leaders or administrators to facilitate the mailing to the families of children with type 1 diabetes?

Given the data access barriers imposed by the Family Educational Rights and Privacy Act (FERPA) interpretation, it was necessary to ask school nurses and administrative staff to facilitate the mailing. The current interpretation of FERPA does not allow BEH access to student health information without parental consent.

5. How many consent forms did MDPH receive?

As of June 2011, MDPH received 65 consent forms from the parents/guardians of children living in Weston, Wellesley and Newton who had been diagnosed with type 1 diabetes and were between 0 -19 years of age prior to December 31, 2009. MDPH received consent forms from five other families who were not included in the analysis. Two of the five individuals were not included because they were older than 19 years of age prior to December 31, 2009 (the time period included in the case definition).

6. What data did the MDPH use to calculate prevalence?

MDPH calculated prevalence estimates and 95% confidence intervals (a measure of statistical significance) using three different data sources:

- 1. Prevalence estimates from the MDPH Environmental Public Health Tracking Program
- 2. Consent form information reported to MDPH by parents/guardians of children/adolescents diagnosed with type 1 diabetes
- 3. Health care provider information on the number of children/adolescents who were with diagnosed with or sought care for type 1 diabetes at their facility in 2009

7. How did MDPH/BEH determine if the pattern of type 1 diabetes in the community or at the neighborhood level was unusual?

To determine whether the prevalence of type 1 diabetes in the three communities differs from what would be expected, data were tabulated to compare the community-specific prevalence estimates to statewide prevalence estimates as well as national prevalence data (as reported in the epidemiological literature). Further, to assess the prevalence of type 1 diabetes in the area of particular concern to the residents, MDPH calculated census tract-specific prevalence estimates. MDPH focused its evaluation on the five census tracts of 3672 (Weston), 4042.01 and 4043.01 (Wellesley), and 3747 and 3748 (Newton). (See the attached map.) A census tract is a geographic subdivision of a city or town designated by the U.S. Census Bureau. Calculating the prevalence of a disease in a census tract gives a better picture of disease occurrence within a particular neighborhood.

8. Did MDPH/BEH review the geographic distribution of type 1 diabetes diagnoses in Weston, Wellesley and Newton and the census tracts of concern in addition to calculating rates?

Yes. In addition to calculating prevalence estimates, residential history information reported on the consent form for each individual diagnosed with type 1 diabetes was mapped using a computerized geographic information system (GIS). Current address and address at diagnosis were mapped. This allowed for an evaluation of the spatial distribution of residences at a smaller geographic level within neighborhoods. The geographic pattern was assessed using a qualitative evaluation of the point pattern of diagnoses in the community. This evaluation also included consideration of the population density of individuals less than 20 years of age residing within the three communities.

9. What other data did MDPH evaluate as part of this investigation?

The consent form also asked parents/guardians if any other family members have been diagnosed with type 1 diabetes. This information allowed MDPH to compare the percentage of children and adolescents in Weston, Wellesley, and Newton who have a positive family history for type 1 diabetes with the percentage expected to have a positive family history, based on the epidemiologic literature.

10. What did the study find regarding the prevalence of type 1 diabetes in each of the three communities as a whole?

The prevalence of type 1 diabetes in children and adolescents at the community level in Weston, Wellesley, and Newton is not statistically significantly different from the nationwide prevalence estimates provided by the SEARCH Study (the largest standardized registry of diabetes in U.S. youth) or the statewide prevalence estimates provided by the MDPH/BEH Environmental Public Health Tracking Program.

11. What did the study find regarding the prevalence of type 1 diabetes in the census tracts of concern?

Prevalence estimates for the three census tracts in Weston and Wellesley (3672, 4042.01, and 4043.01) are statistically significantly higher than the national prevalence estimate. This is not true for the Newton census tracts of interest (3747 and 3748).

12. What did the information collected on the consent forms show regarding the role of family history in the prevalence of type 1 diabetes in the three communities?

It appears that family history of type 1 diabetes played more of a role in the prevalence of type 1 diabetes in Weston, Wellesley, and Newton as well as in the five census tracts, than in the general population. While nationally about 5 to 10% of individuals who are diagnosed with type 1 diabetes would be expected to have a family history of diabetes, 32% of the children/adolescents in Weston, Wellesley, and Newton and 37% of the children/adolescents in the five census tracts in Weston, Wellesley, and Newton with type 1 diabetes were reported to have a family history of type 1 diabetes. Of those 8 individuals that have a parent with a positive family history in the three communities, seven have a father with a previous diagnosis of type 1 diabetes.

13. If a child's father had a previous diagnosis of type 1 diabetes, does that put the child at greater risk of developing type 1 diabetes?

Yes. The risk of type 1 diabetes by age 20 in the offspring of fathers with type 1 diabetes is about three times the risk in the offspring of mothers with type 1 diabetes.

14. What are MDPH's recommendations for future work?

MDPH will complete its review of environmental sites (that is, sites regulated under M.G.L. c. 21E) in the three census tracts in Wellesley and Weston (3672, 4042.01, and 4043.01) to evaluate the potential for exposure to contaminants associated with these sites and any potential relationship to disease prevalence. Particular attention will be paid to any environmental patterns that may emerge suggesting that children who may already be at a higher risk of developing type 1 diabetes share more common opportunities for environmental exposure(s). MDPH will also evaluate on a statewide basis the variability in the prevalence of type 1 diabetes by examining the Environmental Public Health Tracking data (for grades K-8) to identify areas with greater than and less than expected prevalence. The findings from this report coupled with the findings from the environmental site reviews will direct follow-up investigative efforts.

15. Where can I obtain a copy of the report?

The full report is available on the MDPH website at: <u>http://www.mass.gov/dph/environmental_health</u>. See News & Updates.

16. If I have a question about the report findings, who should I contact?

Please call the MDPH/BEH Community Assessment Program at 617-624-5757 or 1-800-240-4266 if you have any questions.



Census Tracts in Weston, Wellesley and Newton, MA