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Sandwich Childhood Cancer Follow-up

QUESTIONS AND ANSWERS

1. Q. What type of information will be reviewed as part of the Massachusetts Department of Public Health's (MDPH) follow-up to the Evaluation of Childhood Cancer Incidence in Sandwich, MA?

A. MDPH will be collecting various types of data in the follow-up evaluation. These include:

- Environmental data (including, but not limited to, private drinking water)
- Childhood cancer incidence data for Mashpee and Barnstable, the two communities adjacent to Sandwich CT 0135
- Interview responses and medical record review for approximately 39 children from Sandwich, Mashpee, and Barnstable diagnosed with cancer from 1995 – 2005

2. Q. What types of questions will be asked in the interviews with parents?

A. MDPH will ask about the child's and parents' residential history, the child's medical history, the biological mother's pregnancy history, parental occupational history, behavioral risks, household exposures and other questions related to the child's school, day care, and camp history.

3. Q. How long will the follow-up evaluation take to complete?

A. It is difficult to predict exactly how long it will take for MDPH to complete this work because of all the factors that are being evaluated. The Department must follow patient privacy and scientific protocols in contacting parents and medical providers. Although adherence to the protocols may add to the time needed to complete the study, it is necessary to protect patient confidentiality. MDPH will provide status updates on the progress of the evaluation in order to keep the public informed.

4. **Q. Why is MDPH required to gain 24A approval and how does it protect the privacy of the families?**
- A. As with all health and medical research, MDPH is required under Massachusetts General Law (M.G.L. c. 111, §24A) to submit an application for authorization to conduct public health research of confidential information. This process ensures that all investigations and studies relating to public health which are either conducted or approved by the MDPH are conducted in a manner which protects the rights and privacy of human subjects to the greatest extent feasible and complies with all applicable state and federal requirements.
5. **Q. How and when will families be contacted to participate?**
- A. Once 24A approval is gained and the interview questionnaire is finalized, MDPH will send a letter and a consent form to each parent of a child diagnosed with cancer between 1995 and 2005 while living in Sandwich, Mashpee, or Barnstable, asking them to participate in the study. The letter will request that consent be given for MDPH to contact the families and to request copies of the mother's and child's medical records. If an individual, previously identified by MDPH as being diagnosed with childhood cancer is now 18 years of age or older, a letter and consent form will be sent directly to that individual.
6. **Q. Who will be interviewed?**
- A. MDPH is interested in interviewing the mothers or primary care-givers of children diagnosed with cancer between 1995 and 2005 who were living in Sandwich, Mashpee or Barnstable at the time of diagnosis.
7. **Q. Why is MDPH focusing the investigation on children?**
- A. This investigation is being conducted as follow-up work to the MDPH *Evaluation of Childhood Cancer Incidence in Sandwich, Massachusetts, 1995 – 2002* that was released in February 2006.
8. **Q. How does MDPH define childhood cancer?**
- A. For purposes of this investigation, childhood cancer is defined as a diagnosis of any type of cancer in an individual between 0 and 19 years of age.
9. **Q. What is known about cancer in children?**
- A. The National Cancer Institute reports that the causes of childhood cancer are largely unknown. Childhood cancers are considered different diseases than cancer diagnosed among adults with respect to risk factors and latency (or developmental) periods. For example, the risk factors typically associated with cancer in adults are different than those associated with the same types of childhood cancer. Unlike cancer in adults, childhood cancer is not thought to be related to personal lifestyle-related risk factors (e.g., tobacco use or poor diet).

Environmental causes of childhood cancer have long been suspected by many scientists but have been difficult to pin down, partly because cancer in children is rare, and partly because it is so difficult to identify past exposure levels in children, particularly during potentially important periods such as pregnancy or even prior to conception.

For more information on childhood cancer, visit the NCI's website at <http://nci.nih.gov/cancertopics/factsheet/NCI-childhood-cancers-research>.

10. Q. Is it unusual for a child to be diagnosed with cancer?

A. In the United States approximately 12,000 children ages 0-19 were diagnosed with cancer in 2001 according to the National Cancer Institute. While this makes cancer the leading cause of death by disease among U.S. children under age 20, cancer is still relatively rare in this age group, with, on average, one or two children developing the disease each year for every 10,000 children in the United States.

11. Q. What towns will be included in the follow-up?

A. MDPH will focus follow-up efforts in the towns of Sandwich, Mashpee and Barnstable, with a particular focus on childhood cancer incidence in census tracts 0135 in sandwich, CT 0131 in Barnstable and CT 0150 in Mashpee. These areas of particular interest include southeastern Sandwich and the two areas of Mashpee and Barnstable that are adjacent to CT 0135 in Sandwich.

12. Q. Why aren't other communities on Cape Cod being included?

A. MDPH is focusing efforts on the area of Cape Cod where an unusual pattern of childhood cancer was observed. A review of childhood cancer elsewhere on Cape Cod does not suggest similar patterns.

13. Q. Are summer residents or former residents of Sandwich being included in the follow-up evaluation?

A. No, the MDPH receives cancer incidence information from the Massachusetts Cancer Registry (MCR) which collects a variety of data for each individual diagnosed with cancer (e.g., date of diagnosis, address at diagnosis, date of birth, etc.). In its February 2006 report, MDPH evaluated the incidence of childhood cancer in Sandwich based on the address reported to the MCR by the child's parent (or child) at the time of diagnosis. Therefore, there is no way to uniformly track all children with or without cancer who may summer on Cape Cod or who have previously lived there. Only children residing in Sandwich, Mashpee, or Barnstable at the time of diagnosis will be included in the follow-up evaluation.

14. Q. Who do I contact for more information?

A. The full report is available on the MDPH website at <http://www.mass.gov/dph/ceh>. The MDPH Community Assessment Program can be reached at:

Phone: (617) 624-5757

Fax: (617) 624-5777