

## **APPENDIX A**

- **Physician Consent Letter**
- **Case Recruitment Letter**
- **Control Recruitment Letter**
- **Participant Follow-up Letter**

April 1, 2002

## PHYSICIAN CONSENT LETTER

Dear Dr.,

We are writing to inform you of our desire to contact the parents of your patient, *name of case* about participating in the Massachusetts Department of Public Health (MDPH), Bureau of Environmental Health Assessment's (BEHA) *Wilmington Childhood Cancer Investigation*.

As you may know, the BEHA investigates reports of adverse health outcomes that may be related to environmental exposures. The BEHA is currently conducting a cancer investigation in the town of Wilmington to address concerns from residents, State Representative James Miceli and the Wilmington Board of Health about a suspected cluster of childhood cancer in Wilmington. The study is being conducted by the BEHA's Community Assessment Unit (CAU).

As part of this investigation, BEHA staff reviewed both the Massachusetts Cancer Registry Data from 1990-2000 and hospital discharge data from 1998-2000 in order to identify all individuals age 0-19 diagnosed with cancer while residing in Wilmington. Your patient, *name of case* was identified during this search as meeting the above criteria.

The MDPH, BEHA understands the sensitivity that is needed when approaching individuals and their families who have been diagnosed with cancer. We are requesting your help by advising us of any reason you feel that we should not contact *name of case* parents about participating on behalf of their child in the *Wilmington Childhood Cancer Investigation*.

If you have no objection to our contacting your patient, we will first send *name of case* parents a letter informing them about the study and asking for their participation (sample letter enclosed). If you prefer to make the first contact, the aforementioned letter will be sent after your initial contact with *name of case* parents. Participation in this study will involve completion of a 1-hour in-person interview with the child's mother or appropriate parent/guardian. Before proceeding with the interview, we will ask the participant for their informed consent (informed consent form enclosed). The interview covers various topics including family medical history, birth characteristics of the child, residential history, parental occupational history, lifestyle factors and hobbies. In addition we will ask that the participant consent to allow MDPH/BEHA's review of the child's medical records and the mother's medical records (if the mother is the participant in the study). The medical records will both provide validation of self-reported information regarding illnesses and drug usage in addition to data that the mother/parent/guardian may be unable to recall. Interviews will also be administered to an appropriate comparison population.

Results from this investigation will be used to help explain patterns of childhood cancer incidence in Wilmington and to possibly propose specific exposures for further investigation.

The *Wilmington Childhood Cancer Investigation* study protocol has been reviewed and approved by both the MDPH Human Research Review Committee, and the MDPH Research and Data Access Review Committee which has assured that our protocol conforms to strict measures of protecting patient confidentiality.

The success of a community investigation of childhood cancer depends on interviewing as many of the eligible patients as possible. We would appreciate if you could let us know as soon as possible of your opinion on contacting *name of case* parents. Please call me at your convenience at (617) 624-5757 or 1-800-319-3042. If I do not hear from you, either CAU staff or I will follow-up by telephone to confirm the appropriateness of contacting *name of case* parents. Thank you for your assistance.

Sincerely,

Theresa A. Cassidy, Chief  
Community Assessment Unit  
Bureau of Environmental Health Assessment

cc: Suzanne K. Condon, Assistant Commissioner, BEHA  
Martha J. Steele, Deputy Director, BEHA  
Patricia A. Miskell, Epidemiologist, CAU, BEHA

## CASE RECRUITMENT LETTER

August 26, 2002

Dear

As you may be aware, concerned residents, State Representative James Miceli and the Wilmington Board of Health contacted the Massachusetts Department of Public Health (MDPH), Bureau of Environmental Health Assessment (BEHA) with concerns about a suspected cluster of childhood cancer in the town of Wilmington. A preliminary review of the available data revealed that from 1987-1995 more children in Wilmington were diagnosed with cancer than would be expected based upon the statewide rate of childhood cancer. In response, the Bureau's Community Assessment Program (CAP) is undertaking an exploratory health study to investigate factors that may help us to better understand the occurrence of cancer among children in Wilmington.

We are writing to request your participation in this important endeavor on behalf of your child, *name of case*. Participation in this study will involve completion of an in-person interview covering various topics including family medical history, birth characteristics of *name of case*, residential history, occupational history, lifestyle factors and hobbies. In addition we will be asking that all study participants consent to a review of both their medical records as well as their child's medical records.

Your participation in this study is completely voluntary. Should you choose to participate, please be assured that any information you provide or which MDPH obtains from your or *name of case* medical records will be held strictly confidential in accordance with state and federal law. The MDPH is prohibited under state law (M.G.L. c. 111, sec. 24A) from releasing information provided by you or obtained from your or your child's medical records in any manner that would allow you or your child to be personally identified.

Please complete the participation form and return it in the enclosed envelope. If you indicate you would like to participate, a staff member from the CAP will contact you within a few weeks to discuss your involvement in this study. In the meantime, if you have any questions, please feel free to contact us at (617) 624-5757 or 1-800-319-3042. Your participation in this study will significantly improve MDPH, BEHA's ability to learn more about the occurrence of childhood cancer in the town of Wilmington. We hope that you will strongly consider taking part in this important public health effort.

Thank you,

Theresa A. Cassidy, Director  
Community Assessment Program  
Bureau of Environmental Health Assessment

## Wilmington Childhood Cancer Investigation Participation Response Form

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Name: \_\_\_\_\_

Relationship to [Name of case]: \_\_\_\_\_

Did [name of case] live in Wilmington on [diagnosis date]? YES NO

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### Are you willing to participate in the Wilmington Childhood Cancer Investigation?

**Yes** Please fill out your contact information below so that MDPH researchers can contact you.

Current Address: \_\_\_\_\_

Telephone Number (h): \_\_\_\_\_

Best Time to Reach You: \_\_\_\_\_

Telephone Number (w): \_\_\_\_\_

**No** Reason(s) for not participating:

\_\_\_\_\_

*Be assured that we will not contact you again. The information you provided above will only be used to assess participation rates.*

*If you feel it may be more appropriate for someone else to participate on behalf of [name of case], please provide his or her name and address.*

Name: \_\_\_\_\_ Relationship to [name of case]: \_\_\_\_\_

Address: \_\_\_\_\_

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## CONTROL RECRUITMENT LETTER

May 26, 2004

Dear ,

As you may be aware, concerned residents, State Representative James Miceli and the Wilmington Board of Health contacted the Massachusetts Department of Public Health (MDPH), Bureau of Environmental Health Assessment (BEHA) with concerns about a suspected cluster of childhood cancer in the town of Wilmington. A preliminary review of the available data revealed that from 1987-1995 more children in Wilmington were diagnosed with cancer than would be expected based upon the statewide rate of childhood cancer. In response, the Bureau's Community Assessment Program (CAP) is undertaking an exploratory health study to investigate factors that may help us to better understand the occurrence of cancer among children in Wilmington.

We are writing to request your participation in this important endeavor on behalf of your daughter, *name of control*. *Name of control* was selected at random from yearbook listings obtained from the Wilmington School District to participate in this study. Interviewing the mothers (or primary care givers) of randomly selected children in addition to the mothers of children who have been diagnosed with cancer will allow us to draw comparisons between the two groups. Participation in this study will involve completion of an in-person interview covering various topics including family medical history, birth characteristics of your child, residential history, occupational history, lifestyle factors and hobbies. In addition we will be asking that all study participants consent to a review of both their medical records as well as their child's medical records.

Your participation in this study is completely voluntary. Should you choose to participate, please be assured that any information you provide or which MDPH obtains from your or *name of control* medical records will be kept strictly confidential in accordance with state and federal law. The MDPH is prohibited under state law (M.G.L. c. 111, sec. 24A) from releasing information provided by you or obtained from your or your child's medical records in any manner that would allow you or your daughter to be personally identified.

Please complete the participation form and return it in the enclosed envelope. If you indicate you would like to participate, a staff member from the CAP will contact you within a few weeks to discuss your involvement in this study. In the meantime, if you have any questions, please feel free to contact us at (617) 624-5757. Your participation in this study will significantly improve MDPH, BEHA's ability to learn more about the occurrence of childhood cancer in the town of Wilmington. We hope that you will strongly consider taking part in this important public health effort.

Thank you,

Theresa Cassidy, Director  
Wilmington Childhood Cancer Study  
Bureau of Environmental Health Assessment

## Wilmington Childhood Cancer Investigation Participation Response Form

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Name: \_\_\_\_\_

Relationship to [Name of Control]: \_\_\_\_\_

Did [name of control] live in Wilmington on [reference date]? YES NO

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### Are you willing to participate in the Wilmington Childhood Cancer Investigation?

**Yes** Please fill out your contact information below so that MDPH researchers can contact you.

Current Address: \_\_\_\_\_

Telephone Number (h): \_\_\_\_\_

Best Time to Reach You: \_\_\_\_\_

Telephone Number (w): \_\_\_\_\_

**No** Reason(s) for not participating:

\_\_\_\_\_

*Be assured that we will not contact you again. The information you provided above will only be used to assess participation rates.*

*If you feel it may be more appropriate for someone else to participate on behalf of [name of control], please provide his or her name and address.*

Name: \_\_\_\_\_ Relationship to [Name of Control]: \_\_\_\_\_

Address:

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\_\_\_\_\_

January 7, 2003

**PARTICIPANT FOLLOW-UP LETTER**

Dear,

On behalf of the Massachusetts Department of Public Health (MDPH), we would like to thank you for your agreeing to be a study participant in the *Wilmington Childhood Cancer Investigation*. We sincerely appreciate your willingness to take some time from your personal schedule to help with this important public health investigation. The success of the Wilmington Childhood Cancer investigation is dependent on the participation of Wilmington resident's like you who have been contacted by MDPH, but unfortunately we have not been able to reach you in order to schedule an interview time.

Your participation in the study involves an in person interview with a MDPH researcher. This confidential interview will take approximately one hour of your time and will be located at the Tewksbury Hospital. The information that will be gathered during the interview will be crucial in helping the MDPH better understand the occurrence of childhood cancer in the town of Wilmington. As mentioned earlier, we have been unsuccessful in reaching you to schedule an interview. We would like to verify that the contact information in our database is correct and that we are contacting you at a convenient time. We have included a participation follow-up form for your convenience. Please complete the form and return it in the enclosed self-addressed stamped envelope.

If you have any questions about the study or would like to contact us to schedule an interview, please feel free to call Karla Segura or me at 617-624-5757 or 1-800-319-3042. Thank you again for supporting this very important health study. Your participation is greatly appreciated. Thank you for your time.

Sincerely,

Theresa A. Cassidy, Director  
Community Assessment Program  
Bureau of Environmental Health Assessment  
Massachusetts Department of Public Health



# Wilmington Childhood Cancer Investigation

## Participation Follow-up Form

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Are you still able to participate in the Wilmington Childhood Cancer Investigation?

**I am still interested in participating in the Wilmington Childhood Cancer Investigation.**

*Please verify your contact information below so that MDPH researchers can contact you.*

Home Telephone Number: \_\_\_\_\_

Work Telephone Number: \_\_\_\_\_

Best Time to Reach You: \_\_\_\_\_

**I am no longer interested in participating in the Wilmington Childhood Cancer Investigations.**

Reason(s) for not participating: \_\_\_\_\_

*Be assured that we will not contact you again. The information you provided above will only be used to assess participation rates.*

*If you feel it may be more appropriate for someone else to participate on behalf of [name of participant], please provide his or her name and address.*

**Name:** \_\_\_\_\_ **Relationship to [Name of participant]:**

\_\_\_\_\_

**Address:**

\_\_\_\_\_