NATIONAL CANCER INSTITUTE

Retinoblastoma Followup Study News Summer 2005

An Update from the Retinoblastoma Followup Study

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Introduction

The National Cancer Institute (NCI) continues to follow the health of more than 1,600 retinoblastoma survivors. The retinoblastoma study is looking at the long-term health problems of this disease. This issue of the newsletter updates study participants about what we have learned.

Retinoblastoma Followup Study investigators, Dr. Margaret Tucker (right) and Ms. Ruth Kleinerman (left), Division of Cancer Epidemiology and Genetics.

New Findings from the Retinoblastoma Followup Study

An important goal of this study is to learn about new cancers that retinoblastoma survivors may face as they grow older. We found an important difference between survivors who had retinoblastoma in one eye (non-hereditary) and survivors who had retinoblastoma in both eyes (hereditary).

Retinoblastoma survivors who had cancer in one eye do not develop another cancer any more frequently than the general population. Survivors who had cancer in both eyes are more likely to be diagnosed with a different type of cancer as they grow older, because they have inherited an alteration in one of their retinoblastoma genes. By age 50, about one out of every three of the hereditary retinoblastoma survivors may develop an additional cancer. The types of cancer they develop most often are bone cancer, soft tissue cancer or melanoma. The alteration in the retinoblastoma gene related to

having cancer in both eyes probably contributes to the development of these new cancers. In addition, the radiation used to cure the retinoblastoma may also increase the risk of developing a bone or soft tissue cancer.

We also found several other types of cancer in hereditary retinoblastoma survivors. Survivors of hereditary retinoblastoma reported more cancer of the lung than the general population. Some female survivors in their 30s and 40s were diagnosed with a soft tissue cancer of the uterus called a leiomyosarcoma. This is a rare type of uterine cancer. Some male survivors were diagnosed with leiomyosarcomas, but on their face and head. If you would like to learn more about leiomyosarcomas, go to www.lmsra.org, although as a governmental agency we may advise you only regarding participation in our own study.

Some female survivors with hereditary and non-hereditary retinoblastoma have reported that they have breast cancer. Breast cancer was more common in survivors who had radiation treatment for their retinoblastoma. We will require more years of followup to determine if breast cancer is related to the radiation treatment used to cure retinoblastoma.

Visit your doctor regularly for cancer screening.

Screening can detect cancer early, when it is more curable. It is important to inform your physician that hereditary RB survivors may be at increased risk for certain cancers, such as soft tissue sarcomas including leiomyosarcomas, bone cancer, and melanoma. For this reason, we recommend regular check-ups with complete physical and skin exams.

Women should obtain regular mammograms starting at age 40. A mammogram can detect breast cancer early.

Early detection of new cancers

Retinoblastoma survivors enjoy long productive lives, and most do not develop additional cancers. However, if you were diagnosed with retinoblastoma in both eyes and received radiation treatment, you have a higher risk of developing another form of cancer. Since being at increased risk for additional cancers is scary, you

should discuss your concerns with your doctor and other members of your health care team.

How to minimize your chances of getting another cancer

You can minimize your chance of developing some new cancers by choosing these healthy behaviors:

■Avoid smoking and second hand smoke. Researchers link both to lung cancer and several other kinds of cancer. If you or anyone in your household smokes, we recommend quitting. Researchers are developing newer approaches to help smokers quit. In collaboration with the Centers for Disease Control and Prevention, and the American Cancer Society, NCI created a website that you can visit at www.smokefree.gov for a new on-line guide to quitting smoking. Call: 1-800-QUITNOW (1-800-784-8669).

■Minimize direct sun exposure. Our recent survey confirmed that those with hereditary retinoblastoma have a higher risk of melanoma. To study this further, NCI is currently inviting individuals with hereditary retinoblastoma who have developed melanoma, and their family members, to participate in a study involving a free skin exam. For further information about this study, please contact Mary Wells, RN at 1-800-518-8474 or marywells@westat.com

Guidelines to reduce sun exposure:

- Minimize midday sun exposure from 10 am – 4 pm in the summer
- Seek shade to avoid sunburns
- Avoid sun tanning
- Wear protective clothing: hats with 4-inch brims, long sleeves, and long pants made of tightly-woven fabrics
- Use sunscreens with SPF (Sun Protective Factor) of at least 30
- Wear sunglasses that block 99-100% UV radiation.

■Avoid other ultraviolet radiation, such as sunlamps, tanning parlors.

Frequently Asked Questions

Why did you start the Retinoblastoma Study?

Our group started the retinoblastoma survivor study in 1984 because we were interested in learning if people are at risk of developing new cancers as they grow older, especially if they received radiation therapy to treat their retinoblastoma.

Why should I continue to participate in this study?

The information you provide about your health adds to our knowledge . Our study group hopes to learn more about the types of cancers that survivors are at risk of developing. Our goal is to follow retinoblastoma survivors over their lifetime. This research should provide useful information on what survivors can expect as they grow older and why they may develop other health problems. Our study is the largest in the United States to follow retinoblastoma survivors for such a long period. Our research would not be possible without your continued participation and cooperation. We appreciate your willingness to provide information about your current health.

Is the information I gave you kept confidential?

We keep the information you give us confidential. The study has a Certificate of Confidentiality. This protects the privacy of the information that you give us. The researchers involved in this study have pledged to keep all information confidential. We report the research results from this study only in the form of statistics. Therefore, no one can identify any participant.

Who should I tell if I develop a new cancer?

Please call or email the information about the cancer, date of diagnosis, your doctor's name and address to Lisa Newman at Research Triangle Institute (RTI) (lnewman@rti.org, phone 1-866-590-7466). Lisa coordinates the study for NCI. She will ask for your written permission to get a copy of the report. We may be able to help you or you can obtain additional information from the Cancer Information Service of NCI, phone: 1-800-422-6237. We also hope that you will give us permission to obtain a copy of the cancer report from your doctor.

If I am thinking of having children, where can I get information about genetic testing for retinoblastoma?

You should consult with your doctor or a genetic counselor about your decision to seek genetic testing. Although we study genes in our research, we do not conduct clinical genetic testing. Several hospitals in the U.S. and Canada conduct this type of testing. A good source for these professionals is the NCI Cancer Genetics Services Directory, (www.cancer.gov/search/geneticsservices/)

Where can I find information on Retinoblastoma on the internet?

Here are some websites that you may find useful:

■ **www.cancer.gov**	National Cancer Institute
■ **www.plwc.org**	People Living with Cancer, sponsored by the American Society for Clinical Oncology

Support groups

■ **www.acscsn.org**	American Cancer Society Cancer Survivors Network
	New England Retinoblastoma Parents Support Group

We published a scientific report describing these results in the Journal of Clinical Oncology:

Kleinerman RA, Tucker MA, Tarone RE, et al. Risk of new cancers after radiotherapy in long-term survivors of retinoblastoma: an extended followup. J Clin Oncol 2005;23:2272-9.

You can obtain a copy at PubMed: http://www.ncbi.nlm.nih.gov/entrez/query.fcgi or you can contact Abigail Ukwuani (NCI) at 301-496-6601 or Ukwuania@mail.nih.gov for a copy.

Contact Ms. Abigail Ukwuani at Ukwuania@mail.nih.gov or 301-496-6601 if you need a copy of the Newsletter compatible with web browser for visually impaired people.

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