

## Letter to be provided to Participant/Family at end of therapy and in follow up clinic.

To Patients and Families Participating in Children's Oncology Group Studies:

Thank you for your participation in a Children's Oncology Group study. Taking part in research is one of the most important ways that we can improve the care of children with cancer. The results from the study, when completed, will be published in the medical literature. The Children's Oncology Group also believes that results from its studies should be made directly available to anyone who participated in this research and is interested in learning the results.

A study report for patients and families will be available at about the same time as the results are published in the medical literature. It is important to note that it may be several years after treatment for all participants is completed that results will be known.

## You may receive the results of the research study in one of several ways:

- a. During your follow-up visits after treatment, you may ask to be given a summary of the study results if the results are available. Your pediatric oncology team can help to answer any questions you may have about the results at that time.
- b. A summary of the results will be posted in the Return of Results section on the Children's Oncology Group website (<a href="https://childrensoncologygroup.org/returnofresults">https://childrensoncologygroup.org/returnofresults</a>). You can search for the study in which you are interested by study ID number or title, by keyword, or by disease type. Recall that the final study results may not be available for a long time after you took part.
- c. If a result summary is available for the study in which you are interested, click on "View Results" under the Summary of Results column.

We value your feedback! Please provide feedback about any result summaries you read by completing a brief survey. A link to the survey is provided at the end of each summary.

d. You may also register with the COG website to be notified by email when the results are posted or updated. Please go to the Return of Results section on the Children's Oncology Group website (<a href="https://childrensoncologygroup.org/returnofresults">https://childrensoncologygroup.org/returnofresults</a>), find the study in which you are interested and click on "Register Here" under the Summary of Results column. Then enter your email address to receive notification when a summary is first posted or later updated. If you choose this option, it is your responsibility to update your email if there are any changes over time.

Regardless of which way you to choose to get the results, you may discuss any questions you have with your pediatric oncology team.

If you have any questions about how to access the results, please contact your pediatric oncology team or the COG Help Desk at HelpDesk@childrensoncologygroup.org.