



# REGISTRY NEWSLETTER

## Welcome!

Happy New Year from the Registry team. 2025 was a year filled with changes at the Registry. We moved offices. Our team is still located at the Children's Minnesota Minneapolis campus, but we are now located at 2545 Chicago Avenue, Suite 515, Minneapolis, MN 55404.

We hosted our first ever combined *DICER1* Symposium & Family meeting, this past May. Over 200 patients, families, physicians, care team members, and researchers joined together from around the world as we discussed *DICER1* surveillance and testing. More information about the Registry's current *DICER1* surveillance guidelines can be found below.

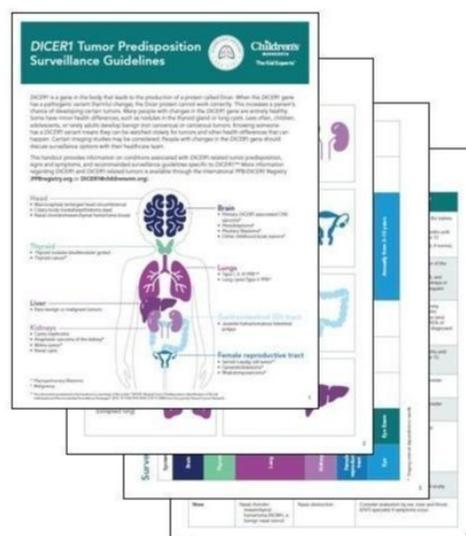
Collaborations at the Registry have continued to grow and change. We continue to learn more in the area of *DICER1* biology as we collaborate with our partners on PDX models, organoids, tumor microarray (TMA) development, biomarker analysis and more. We are excited to further these investigations as we head into 2026 - in the pursuit of our mission to improve outcomes for patients with PPB, other *DICER1*-associated conditions, and stromal tumors.

## *DICER1* Surveillance Guidelines

The Registry's current *DICER1* surveillance guidelines are highlighted in the manuscript [\*DICER1\*-Related Tumor Predisposition: Identification of At-risk Individuals and Recommended Surveillance Strategies](#).

The findings included in this article are summarized in the Registry's *DICER1* Surveillance Education document. We hope you, your families, and your care teams find this tool helpful.

Additionally, this content was presented at the 2025 *DICER1* Symposium & Family Meeting. The video of this presentation is linked below.





[Request Surveillance Education Document](#)

[View Presentation](#)

## 2026 *DICER1* Symposium & Family Meeting



We invite you to join us for the 2026 *DICER1* Symposium & Family Meeting on Thursday, April 9, from 9:00 a.m. to 1:00 p.m. CDT.

[View Agenda](#)

\*Agenda may be subject to change\*

Registration for this event is now open. You can register for the event below. Registration is free, except for those seeking genetic counselor (NSGC) continuing education units.

### General Registration:

[General Registration](#)

## Continuing Education Registration:

CME (AMA PRA), ANCC, and NSGC CEUs

Continuing Ed Registration

Please email [DICER1@childrensmn.org](mailto:DICER1@childrensmn.org) with any registration questions.

## Ovarian Juvenile Granulosa Cell Tumor

Ovarian juvenile granulosa cell tumor: A report from the International Ovarian and Testicular Stromal Tumor and International Pleuropulmonary Blastoma/DICER1 Registries summarizes the clinical presentations and outcomes of patients with juvenile granulosa cell tumor (JGCT). This analysis includes 70 Registry participants with a history of JGCT.

Mitotic index, a unit of measurement for the rate of cell division, was identified as a prognostic factor linked to recurrence. Of the 14 cases of recurrent JGCT, all cases with a known mitotic index exhibited a high mitotic index (greater than 19 mitoses per 10 high power fields). Consequently, it is recommended that all JGCT diagnoses undergo mitotic index assessment.



Thank you to everyone whose participation made this discovery possible, and thank you to Anne Harris, MPH (pictured above), who led this analysis. Anne has been with the Registries since 2011 and helped with the initiation of the OTST Registry. We are grateful for all of her work and her dedication to improving outcomes for those affected by stromal tumors.

## DICER1 Cooperating Variants

In collaboration with Dr. Pratilas' team at Johns Hopkins University, the Registry published a [case report](#) focused on alterations in the RAS signaling pathway in *DICER1*-related tumors. This report followed two patients who had tumors with alterations in the RAS pathway; one had a *HRAS* variant and the other had a *BRAF* variant.

The patients' responses to molecularly targeted agents were assessed during their tumor journey. In both cases, disease stabilization was seen temporarily before they each experienced further tumor progression. There is much yet to learn regarding the relationship between *DICER1* and other tumor-related genes as well as identifying the most effective way to use molecularly targeted agents for *DICER1*-related tumors.



The Registry continues to investigate how variants in other gene pathways interact with *DICER1* variants to drive tumor growth and progression. Through analyses like this one as well as through lab-based research, we strive to uncover more in this developing area.

## Meet Reggie



Reggie is the Registries' -80°C freezer, which houses processed biomarker samples until the samples can be analyzed.

The Registry has been collecting biomarker samples since 2016, and so far, nearly 1,900 samples have been collected. Samples are analyzed for *DICER1* circulating tumor DNA. Results are correlated with clinical data to see if *DICER1* circulating tumor DNA can be used as a blood-based biomarker to identify *DICER1*-related tumors. This research connects to the Registry's third strategic pillar of our mission - develop new ways to diagnose and follow children with *DICER1*-related cancers.

We are grateful for each and every one of the biomarker samples collected. Thank you to all of the participants, families, clinical teams, and lab members that make this research possible. Your participation and support are invaluable to this effort.

## Opportunities to Participate



Including vegetables regularly in one's diet is a powerful lifestyle habit to help boost your health.

We would love to see your children's favorite vegetable recipes. To participate in the challenge, a copy of your child's recipe along with a photo of their vegetable creation can be emailed to the Registry team at [DICER1@childrensmn.org](mailto:DICER1@childrensmn.org).

Selected recipes will be shared at the 2026 *DICER1* Symposium and Family Meeting.

[Submit Recipe](#)

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Participation in the Registries spans worldwide. Each person's participation helps us learn more about these rare conditions, and we are honored to be a part of this global mission. We welcome all ages (children and adults) to participate from anywhere in the world.



Anyone with a current or previous *DICER1*-associated condition is eligible to participate in the PPB/*DICER1* Registry, regardless of whether or not they have had *DICER1* testing. Additionally, we welcome those with a known germline *DICER1* variant to participate, even if they have been otherwise healthy and do not have a history of a *DICER1*-associated condition.

Anyone with an ovarian or testicular stromal tumor is eligible to participate in the OTST Registry.

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For more information about participation, you can visit us at the links below.

[PPB/\*DICER1\* Registry](#)

[OTST Registry](#)