

# 2019 NPCR TENNESSEE SUCCESS STORY

## Tennessee Cancer Registry: Dr. Martin Whiteside

### Documentation of Wilms Tumor histologic presentation in a statewide cancer registry: Importance to Prognostic Assessment

# NATIONAL PROGRAM OF CANCER REGISTRIES SUCCESS STORY

**SUMMARY:** Wilms Tumor is the most common childhood kidney cancer in those that are less than 15 years of age and the fourth most common pediatric cancer overall. As a result, Wilms Tumor is a major contributor to childhood morbidity in the U.S., but thankfully, the overall 5-year survival rate for Wilms Tumor patients is about 92%. Patient prognosis is profoundly affected by the histological presentation of the tumor, i.e. whether “favorable” or “unfavorable” histology. If the patient is reported to present without anaplasia or has focal anaplasia, this is designated as “favorable histology”; however, the presence of diffuse anaplasia is synonymous with “unfavorable histology”. Histologic presentation is also an important tumor characteristic that drives the treatment decision-making process. As such, this information is critically important to capture during abstraction of patient medical records before submission to central cancer registries due to its importance in patient treatment and prognosis. Since no coded data items exist—including site-specific data items—that capture histologic presentation in the standard tumor abstract, this information could be provided in the tumor abstract text. However, this vital information is not provided in most abstracts submitted to the Tennessee (TN) Cancer Registry (TCR).

**CHALLENGE:** All Wilms Tumor cases, 130 total, within the TCR main cancer database diagnosed during the years 2004–2015 underwent quality control analysis. Dr. Whiteside, TCR Program Director, had to perform this analysis given the unavailability of cancer registrar staff that was dedicated to completing mandatory cancer registry operations. Firstly, all 130 cases were successfully evaluated by comparing the submitted histology code with the submitted text in the abstract. One incorrectly coded case was identified that should have been coded as a renal cell carcinoma and was excluded from the analysis.

Secondly, after reviewing the text fields for any mention of favorable/unfavorable histologic presentation, pathology reports were obtained from the reporting facilities to determine if histologic presentation was provided. This took significant time and effort and Dr. Whiteside had to perform this step, given that cancer registrar staff was not available to assist. Additional complexity associated with the acquisition of pathology reports involved ensuring that the pathology report principally associated with curative-intent surgery was obtained rather than ancillary reports prepared either before or after curative-intent surgery.

Thirdly, analysis revealed that some hospital-based cancer registrars may not include a detailed description of histologic presentation in the appropriate text field of the abstract. Thus, an additional challenge involves educating cancer registrars statewide about the importance of including enough text to document histologic presentation of Wilms Tumor cases.

**SOLUTION:** This project was made possible with the input of internal and external TCR stakeholders. TCR’s program manager consulted with Dr. Whiteside on evaluating text fields in a standard cancer abstract. This included reviewing text fields for documentation of histology of the tumor and ancillary information about tumor histology, such as whether favorable or unfavorable histology was noted during examination of Wilms Tumor surgical pathology specimens.

Indirectly, the American Cancer Society (ACS) provided significant assistance directing the completion of this quality assurance study. The ACS has webpages dedicated to presenting layperson-level information about Wilms Tumor, including information about early detection, staging, potential provider questions, etc. One specific webpage entitled, “Survival Rates for Wilms Tumors” contains a table that details survival rates by stage at diagnosis stratified by histologic presentation; this table provided an understanding of the significance of histologic presentation to patient prognosis.

This study would not have been possible without the dedicated support and consultation received from staff members at the Vanderbilt University Medical Center (VUMC). Specifically, a pediatric general and thoracic surgeon—Dr. Harold N. Lovvorn, III—at VUMC provided significant assistance with study design. He provided the initial understanding of the relationship of tumor anaplasia to patient outcomes and how anaplasia related to the concept of favorable and unfavorable histologic presentation. Dr. Lovvorn has collaborated with TCR staff for many years performing research dedicated to a better understanding of childhood cancer, in particular childhood kidney cancers.

Lastly, the TN Tumor Oncology Data Analyst Association (TODAA), the main association in the state supporting cancer registrars statewide, disseminated the results of this study. Leaders of TODAA learned that TCR staff were conducting this Wilms Tumor

quality assurance study and invited Dr. Whiteside to present the results at the annual TODAA educational conference on October 18, 2019. Most of the attendees at the TODAA conference are Certified Tumor Registrars that work for Commission-on-Cancer (CoC)-accredited hospitals, of which there are currently 30 CoC-accredited facilities in TN.

**RESULTS:** There were a total of 130 Wilms Tumor cases extracted from the TCR main cancer database (CRSPlus), of which one case was incorrectly coded, as previously mentioned, thus leaving 129 cases for evaluation. All cases evaluated were TN residents at the time of diagnosis. The sex, age, diagnosis stage and race distribution among the cases were as follows. There were 50 males (38.8% of cases) and 79 females (61.2% of cases), which is consistent with other studies that have demonstrated a slight excess in the number of female patients in this population. The median age of patients in this study was 3 years old, which is also consistent with prior published studies that observed the median age at 3.5 years of age. Most of the cases in this study (N=57, 44.2% of all cases) were diagnosed at the localized stage, also consistent with other studies that have demonstrated approximately 40-45% of all cases are diagnosed at the localized stage (1). Black children accounted for 25.6% of all cases in this study. All cases were histologically confirmed at diagnosis.

During the next phase of the study, text documentation of histologic presentation was evaluated. In the state of TN, text is required for all abstracts to document treatment, primary site, histology and other codes provided in the tumor abstract. Of the 129 cases evaluated, 62 (48.1%) had text documentation of histologic presentation specific to unfavorable/favorable status, whereas 67 cases (51.9%) lacked this documentation, though text may have been provided for other histologic characteristics. Statistics for text documentation of histologic presentation were stratified by facility, specifically for those facilities that diagnosed and/or treated greater than 10 cases during the study period, of which there were 4 facilities. The following percentages of text documentation of histologic presentation were observed for these facilities: 11.8%, 15.8%, 45.5% and 90.2%. Thus, one facility submitted 90.2% of Wilms Tumor abstracts with text documentation of histologic presentation, whereas all other facilities only submitted a minority of Wilms Tumor abstracts containing this vital information. However, when final pathology reports were obtained for all 129 patients, it was observed that all, except for one, pathology report contained sufficient information to document histologic presentation.

The content provided in facility text submitted with a patient abstract was compared to the pathology report. For those cases containing text documentation of histologic presentation, there was a 100% match between the text submitted documenting histologic presentation and what was available in the pathology report. It’s worth noting that not all patients with “unfavorable” histologic presentation had this information documented in the patient abstract text, which is essential given the seriousness of “unfavorable” histologic presentation and the importance of this to the treatment decision-making process. For all cases that had pathologic evidence of “unfavorable” histologic presentation, 66.0% were sufficiently documented in the text of the patient abstract. For all cases with pathologic evidence of “favorable” histologic presentation, 47.5% were sufficiently documented in the text of the patient abstract.

**SUSTAINING SUCCESS:** The information from this study was presented at the North American Association of Central Cancer Registries’ Annual Conference in June 2019. In addition, leaders of the state’s tumor registrar’s association learned of this study and have invited Dr. Whiteside to speak at the annual educational conference on October 18, 2019. In attendance will be the tumor registrars representing most of the Commission-on-Cancer-accredited facilities in TN. Sustaining success will be to continue to highlight this information at the state’s regional tumor registrar’s meetings and encourage TCR educational staff to include information on Wilms Tumor histologic presentation in phone and/or in-person training sessions with facility staff, when appropriate. Effectiveness of outreach efforts will be measured by noting that future abstracts contain text information documenting histologic presentation in a larger percentage of Wilms Tumor patients.

#### CONTACT INFORMATION:

Tel.: 800-547-3558

Website: <https://www.tn.gov/health/health-program-areas/tcr.html>

#### REFERENCES

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