

# PDCS

## Neuroblastoma

## Retinoblastoma

## Hepatoblastoma

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## 2025 Implementation

- **Required by SEER 2025+**
  - Every facility in Iowa must report Pediatric staging and SSDI as applicable
  - Required by Iowa: **Ages 0-39**
    - Software will determine which cases will go into a specific Pediatric Schema
  - You will be assigning Ped Stage Items and SSDIs (when applicable) **in addition to**
    - AJCC (if applicable)
    - EOD
    - SSDIs/Grade

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## Where to Find Information:

- **SEER Website: RSA page – Pediatric Data (2024+)**
  - Schemas/Coding Structure
    - **2025:** <https://staging.seer.cancer.gov/pediatric/home/1.2/>
    - **2026:** <https://staging.seer.cancer.gov/pediatric/home/1.3/>
- **Pediatric Staging Manual (2024+)**
  - NAACCR Website: <https://www.naacccr.org/pediatric-resources/#1733928553790-ca5cfb7b-2f2e>
- **Questions – Ask a SEER Registrar**
  - <https://seer.cancer.gov/registrars/contact.html>



PEDIATRIC DATA COLLECTION SYSTEM (PDCS)
PEDIATRIC STAGING MANUAL
The Pediatric Staging Manual will be expanded over the course of several years and will be a comprehensive guide for coding of pediatric cancers.
<ul style="list-style-type: none"> <li>• <a href="#">Pediatric Staging Manual v.1</a> (PDF, 187 KB)</li> <li>• <a href="#">Appendix</a> (PDF, 1.1 MB)</li> <li>• <a href="#">Appendix</a> (PDF, 261 KB)</li> <li>• <a href="#">Appendix</a> (PDF, 115 KB)</li> </ul>
TORONTO STAGING GUIDELINES
PEDIATRIC TRAININGS
PEDIATRIC CODING QUESTIONS
REFERENCES

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# Neuroblastoma

**Refers to nerves –**  
develops in peripheral  
nervous tissue

**Refers to cell  
type –** develops  
in immature and  
developing cells

**Refers to a group  
of cells or a tumor**

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# Neuroblastoma

## Primary Site/Histology/Behavior:

- **Primary:** C000-C699, C739-C750, C754-C809; **Histology:** 9490, 9500; **Behavior:** 3
- **Primary:** C700-C729, C751-C753; **Histology:** 9490, 9500; **Behavior:** 0,1,3

## Pediatric Stage:

- **Ped Primary Tumor:** 100-800; 999
- **Ped Regional Nodes:** 000-800; 999
- **Ped Mets:** 00-70; 99

## Ped SSDI:

- INRGSS
- n-MYC Amplification
- INPC

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# Neuroblastoma

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- Rare cancer of early nerve cells (neuroblasts) of the sympathetic nervous system
    - Many start in the abdomen
      - Adrenal gland or sympathetic nerve ganglia
        - Nerve cells and cells in the medulla of the adrenal gland start as neuroblasts in a growing fetus
    - Others can be anywhere along sympathetic nervous system
      - Spine, chest, neck, or pelvis
  - Most common in infants and children under 5
    - Rare for people over the age of 10

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## Neuroblastoma – Ped Primary Tumor

Ped Primary Tumor is based on surgical resection of the primary site only **WITH** or **WITHOUT** neoadjuvant therapy

Surgery	Extension	Code	SS
Complete resection	Localized tumor confined to one side of the body and one area	100	1
	Regional tumor confined to one side of body and one area	300	2
Incomplete resection	Localized tumor confined to one side of the body and one area;	200	1
	Regional tumor confined to one side of the body, greater than one area;	400	2
Not able to resect primary	Tumor starts in or crosses the vertical midline (spine) of the body; Can't be surgically removed	600	7

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## Neuroblastoma – Ped Primary Tumor

- **Code 700** – Further contiguous extension
- **Code 800** – No evidence of primary tumor
- **Code 999** – Unknown; not documented
  - No Surgical Resection done/not recommended
  - Clinical work up only
  - Unknown if surgery done

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## Neuroblastoma – Ped Regional Nodes

Description	Notes	Code
No regional LN involved		<b>000</b>
Ipsilateral regional LN	Same side as the primary site	<b>100</b>
Contralateral regional LN	Opposite side as the primary sites; Bilateral involvement	<b>300</b>
Regional LN NOS	Unknown if ipsilateral, contralateral or bilateral	<b>800</b>
Unknown	Not documented; Not assessed	<b>999</b>

Based on clinical and/or pathologic information **WITH** or **WITHOUT** neoadjuvant therapy; Used EOD and SS based on primary site to determine if involved LN is regional or distant

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## Neuroblastoma – Ped Mets

Description	Notes	Code
No distant mets	Stated no distant mets; Imaging/workup negative for metastatic disease; Benign/Borderline tumor	<b>00</b>
Distant LN	Only distant LN involved	<b>10</b>
Skin involved	<b>WITH or WITHOUT</b> distant LN	<b>20</b>
Liver involved	<b>WITH or WITHOUT</b> distant LN or skin	<b>30</b>
Bone marrow involved	<b>WITH or WITHOUT</b> distant LN, skin, or liver	<b>40</b>
Bone involved	<b>WITH or WITHOUT</b> distant LN, skin, liver, or bone marrow	<b>50</b>
Other specified mets; Distant mets NOS	Involvement of sites other than those listed in codes 10-50	<b>70</b>
Unknown	Not documented in the record; Distant mets not stated	<b>99</b>

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# Neuroblastoma – Ped SSDI: INRGSS

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- International Neuroblastoma Risk Group Staging System (INRGSS)
  - Based on **clinical work up** and **image-defined risk factors**
  - Another name: INRG
- **Image-Defined Risk Factors**
  - Assessment of whether patients have none, or one or more image-defined risk factors – prior to any treatment
- **Ascites and pleural effusion**
  - Considered metastatic disease if they are remote from the body compartment of the primary tumor

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## Neuroblastoma – Image Defined Risk Factors

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Body Compartment	Extension
Neck	Encasing carotid and/or vertebral artery and/or internal jugular vein; Extend to base of skull; Compress the trachea
Cervico-thoracic junction	Encase brachial plexus root; Encase subclavian vessels and/or vertebral and/or carotid artery; Compress the trachea
Thorax	Encase aorta and/or major branches; Compress trachea and/or principal bronchi; Low mediastinal tumor, infiltrate costovertebral junction (between T9 & T12)
Thoraco-abdominal	Encase aorta and/or vena cava
Abdomen, pelvis	Infiltrate porta hepatis and/or hepatoduodenal ligament; Encase branches of SMA at mesenteric root; Encase origin of coeliac axis, and/or SMA; Invade one or both renal pedicles; Encase aorta and/or vena cava Encase iliac vessels; Pelvic tumor crosses sciatic notch
Intraspinal tumor	More than 1/3 of spinal canal in axial plane invaded and/or perimedullary leptomeningeal spaces are not visible and/or spinal cord signal abnormal
Adjacent organs/structures	Pericardium; Diaphragm; Kidney; Liver; Duodeno-pancreatic block; Mesentery
2 Body Compartment	Ipsilateral Tumor: Neck-chest; Chest-abdomen; Abdomen-pelvis

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# Neuroblastoma – Ped SSDI: INRGSS

Stage	Description	Notes	Code
L1	Localized tumor that doesn't involve vital structures; Confined to 1 body compartment; No IDRF's	Intraspinal extension that doesn't fulfil criteria for an IDRF is c/w Stage L1	1
L2	Locoregional tumor with evidence of IDRF's; Tumor ipsilaterally contiguous within body compartment	Non-contiguous disease is coded as M	2
M	Distant metastatic disease; Noncontiguous disease; Distant LN	For patients less than 18 months – see Stage MS	3
MS	For patients <b>less than 18 mo only</b> : Metastatic disease confined to: <ul style="list-style-type: none"> <li>Bone marrow</li> <li>Skin</li> <li>Liver</li> </ul>	Bone marrow – MIBG scintigraphy must be negative in bone and bone marrow If MIBG or PET/CT show bone marrow involvement, a BM bx will be performed *MIBG can be treatment for high risk NBL patients	4
	Not documented in record; Not assessed		9

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## Neuroblastoma - Ped SSDI: n-MYC

- n-MYC Amplification is a gene that normally regulates cell growth
  - Indicator of poor prognosis and unfavorable outcomes
- The status of n-MYC is after a pathologic specimen is obtained
  - Source: molecular pathology report (may be in an addendum)
  - Physician statement can be used without more information available

Description	Code
Not amplified/negative	0
Amplified/positive	1
Gain	2
Test ordered, results not in chart	7
Not documented; unknown; not applicable (secondary to previous chemo); Not assessed; Unknown if assessed	9

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## Neuroblastoma – Ped SSDI: INPC

- **International Neuroblastoma Pathology Prognostic Classification (INPC)**

- Favorable vs Unfavorable histology
- Based on pathologic findings
  - **Source document:** pathology report without neoadjuvant therapy
  - Physician statement can be used of unfavorable or favorable histology when no other information; as long as the results are from biopsy or resection without neoadjuvant therapy
- **Criteria:**
  - Age
  - Neuroblastic maturation
  - Schwannian stromal content
  - Mitosis-karyorrhexis index (MKI)
  - Degree of differentiation (grade)

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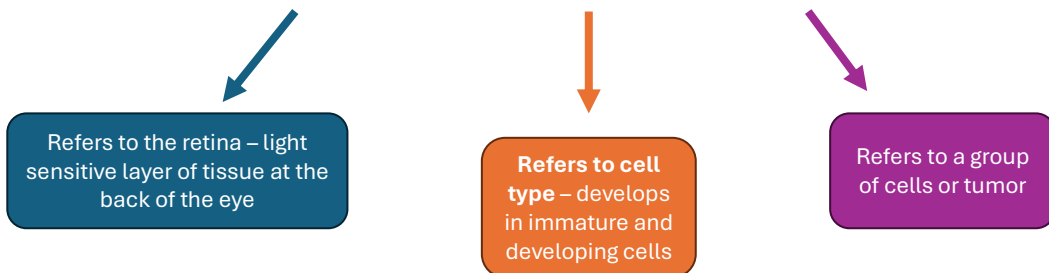
## Neuroblastoma – Ped SSDI: INPC

Description	Code
Unfavorable	<b>0</b>
Favorable	<b>1</b>
Test ordered, results not in chart	<b>7</b>
Not documented; Can't be determined by pathologist; INPC not assessed or unknown if assessed; INPC assessed only at post-therapy (following neoadjuvant therapy) surgical resection	<b>9</b>

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# Retinoblastoma



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## Retinoblastoma

**Primary Site:** C69\_

**Histology:** 9510-9514

**Behavior:** 3

**Pediatric Stage:**

- **Ped Primary Tumor:** 100-800; 999
- **Ped Regional Nodes:** 000-800; 999
- **Ped Mets:** 00-70; 99

**Pediatric SSDI:**

- IRSS Stage for Eye-2

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# Retinoblastoma

- A rare ocular cancer that most often occurs in children under the age of 4
  - There are almost no cases in children over the age of 6
- Often a family history is done by a genetic counselor
  - Caused by the inactivation of both alleles of the RB1 gene
- Primary site is **C69.2** (Retina)
- Histology is usually **9510/3** but there are more specific codes that can be used if listed as such in the path report
- Bilateral disease is a **SINGLE** primary regardless of timing

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## Retinoblastoma – Ped Primary Tumor

- **Bilateral retinoblastoma**

- Record the stage of the eye with the **more advanced/higher stage** in **Ped Primary Tumor**
  - Code the eye with the lesser/lower stage in the **SSDI: IRSS Stage for Eye-2**

- Pathological staging information from enucleation takes priority over clinical
  - **EXCEPTION:** If neoadjuvant therapy given and clinical disease is more extensive, code based on clinical findings



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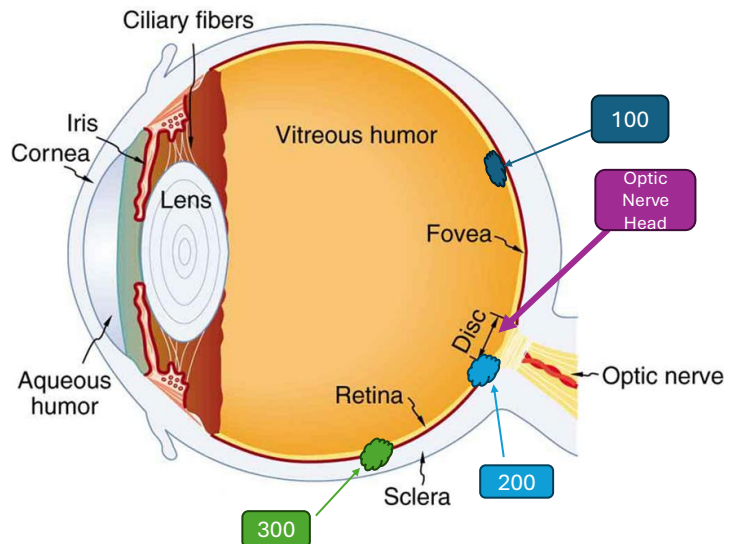
# Retinoblastoma – Ped Primary Tumor

	Location	Extension	Code	SS
21	Intraocular Tumor	<b>WITHOUT</b> local invasion, focal choroidal invasion, or pre- or intralaminar involvement of optic nerve; Confined to retina; Localized	<b>100</b>	<b>1</b>
		<b>WITH</b> local invasion – <i>see list in manual</i>	<b>200</b>	<b>1</b>
		Advanced <b>WITH</b> significant local invasion – <i>see list in manual</i>	<b>300</b>	<b>1</b>
	Extraocular Tumor	Tumor at transected end of optic nerve or meningeal spaces around optic nerve; Full-thickness invasion of sclera <b>WITH</b> invasion of – <i>see list in manual</i>	<b>400</b>	<b>2</b>
	No evidence of primary tumor	No primary tumor found	<b>800</b>	<b>9</b>
		Not documented; unknown extension; PT can't be assessed	<b>999</b>	<b>9</b>

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## Retinoblastoma – Ped Regional Nodes

Description	Code
No regional LN involved	000
23 Cervical, NOS Mandibular, NOS <ul style="list-style-type: none"> <li>• Submandibular (submaxillary)</li> </ul> Parotid, NOS <ul style="list-style-type: none"> <li>• Infra-auricular</li> <li>• Preauricular</li> </ul>	300
Regional LN, NOS; Lymph nodes, NOS	800
Unknown; Regional LN not assessed or unknown if assessed	999

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## Retinoblastoma – Ped Mets

- 
- **Trilateral retinoblastomas (TRb)**
    - Bilateral intraocular tumors **AND**
    - Related brain tumor
      - Typically, the pineal gland
  - This is **NOT** coded in Ped Mets
  - Code in the **SSDI – Heritable Traits (NAACCR #3856)**
    - Germline mutation in RB1 gene
      - Associated with bilateral disease, family history of retinoblastoma, presence of concomitant CNS midline embryonic tumor, or retinoblastoma w/ intracranial primitive neuroectodermal tumor (trilateral retinoblastoma)

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## Retinoblastoma – Ped Mets

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Description	Code
No distant mets; Imaging is negative for distant mets; physician states no mets	00
Distant LN	10
Distant mets to any organ EXCEPT CNS; Carcinomatosis; Codes 10+30	30
CNS Parenchyma; CSF; Any combination of 10, 30, and 50	50
Distant mets, NOS	70
Unknown; Distant mets not stated; not documented in record	99

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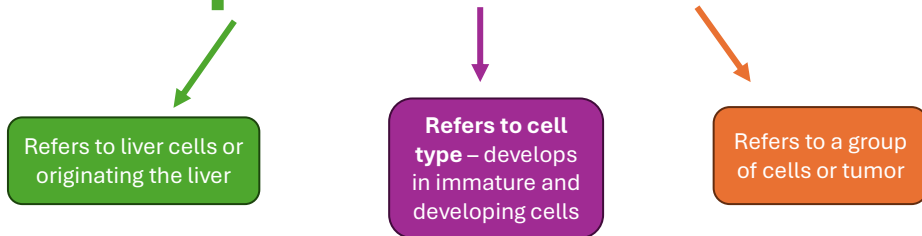
## Retinoblastoma – Ped SSDI: IRSS Stage for Eye-2

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Stage	Description	Notes	Code
0	Tumor confined to globe; No enucleation; Patient treated conservatively with either focal therapies or chemo		0
1	Enucleation w/ negative margins; Completely resected histologically		1
2	Enucleation w/ positive or microscopic residual tumor		2
3	Regional extension, involve: orbit, preauricular extension, or cervical LN involvement		3
4	Distant mets		4
NA	Unilateral retinoblastoma	Only one eye involved	7
	Not documented in the record; unknown; IRSS not assessed or unknown if assessed		9

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# Hepatoblastoma



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## Hepatoblastoma

**Primary Site:** C220

**Histology:** 8970

**Behavior:** 3

**Pediatric Stage:**

- **Ped Primary Tumor:** 150-800; 999
- **Ped Regional Nodes:** 000-800; 999
- **Ped Mets:** 00-70; 99

**Pediatric SSDI:**

- Pretext Clinical Staging

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## Hepatoblastoma – Ped Primary Tumor

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Resection	Margins	Extension	Ped PT	SS
Surgical resection (Pathologic Assessment ONLY)	Negative or Unknown	Confined to one lobe of liver <b>WITH</b> or <b>WITHOUT</b> vascular invasion ( <i>see list in manual</i> )	<b>150</b>	<b>1</b>
		Confined to liver but more than 1 lobe <b>WITH</b> or <b>WITHOUT</b> vascular invasion ( <i>see list in manual</i> )	<b>250</b>	<b>2</b>
	Positive	See code 150	<b>175</b>	<b>1</b>
		See code 250	<b>275</b>	<b>2</b>
Partial resection		Confined to liver <b>WITH</b> or <b>WITHOUT</b> vascular invasion; incomplete resection; unresectable; presses into vital tissue in liver	<b>350</b>	<b>2</b>
		No evidence of primary tumor	<b>800</b>	<b>9</b>
		Unknown; not documented;	<b>999</b>	<b>9</b>

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## Hepatoblastoma – Ped Regional Nodes

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Description	Code
No regional LN involved	<b>000</b>
Caval Hepatic, NOS: Hepatic artery; Hepatic pedicle; IVC; Porta hepatis (portal) Hepatoduodenal ligament Periportal Portal vein	<b>300</b>
Inferior phrenic nodes	<b>700</b>
Regional LN NOS; Lymph Nodes NOS	<b>800</b>
Unknown; Regional LN not assessed or unknown if assessed	<b>999</b>

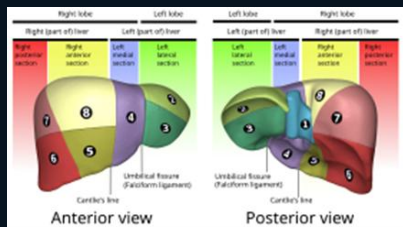
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# Hepatoblastoma – Ped Mets

	Description	Notes	Ped Mets	SS
	No distant mets	Stated to have no mets; Imaging negative for distant mets	00	
31	Diaphragm; Ligaments; Peritoneum	Omentum – lesser and NOS (see code 20 for Greater Omentum); <i>See full list in manual</i>	10	2
	Further contiguous extension	Greater Omentum; Pancreas; Pleura; Stomach	20	7
	Distant LN	<i>See list in manual</i>	30	7
	Lungs		40	7
	Carcinomatosis	Distant mets <b>WITH</b> or <b>WITHOUT</b> distant LN; Other specified mets; Distant mets, NOS	70	7
	Unknown	Not stated or documented in record	99	

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## Hepatoblastoma Ped SSDI: Pretext Clinical Stage



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- This is the extent of involvement **prior to treatment** (clinical)
  - Extent of involvement within the 4 lobes of the liver
  - Based on **clinical imaging**
- It is used as a central component of risk stratification schemes that define treatment
- **Sections/Segments of liver:**
  - Caudate section: Segment 1
    - Involvement of caudate is at a minimum Stage 2
  - Left lateral section: Segments 2 & 3
  - Left medial section: Segments 4A & 4B
  - R anterior section: Segments 5 & 8
  - R posterior section: Segments 6 & 7

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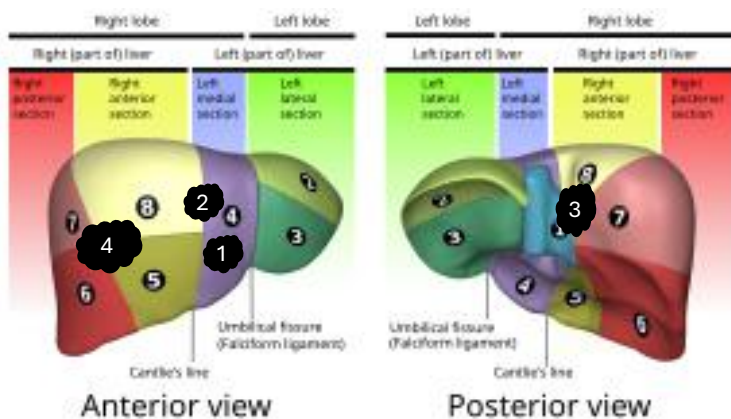
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# SSDI: Pretext Clinical Stage

Description	Notes	Code
One section involved	Three adjoining sections are tumor free; Stage 1, Pretext 1	<b>1</b>
One or two sections involved	Two adjoining sections are tumor free; Stage 2, Pretext 2	<b>2</b>
Two or three sections involved	One adjoining sections are tumor free; Stage 3, Pretext 3	<b>3</b>
Four sections involved	Four sections involved; Stage 4, Pretext 4	<b>4</b>
Not documented	No clinical imaging information; Unknown; Not in documents; Not assessed or unknown if assessed	<b>9</b>

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## SSDI: Pretext Clinical Stage



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# Registrar Resources...

- **PDCS Manual – Appendix I**

- NAACCR website

<https://www.naacccr.org/pediatric-resources/#1733928553790-ca5cfb7b-2f2e>

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- **PDCS Coding for Stage and SSDI:**

- SEER website

- **2025:** <https://staging.seer.cancer.gov/pediatric/home/1.2/>

- **2026:** <https://staging.seer.cancer.gov/pediatric/home/1.3/>

- **Specific Training:**

- NACCR Training website:

<https://education.naacccr.org/pediatric-data-collection-system-training>

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# Questions?

- Questions on PDSC Manual and/or coding instructions:

- **Ask a SEER Registrar:**

- <https://seer.cancer.gov/registrars/contact.html>

- ICR specific questions on PDSC staging/coding:

- **Melissa Riddle, ODS-C**

- Education/Training

- [melissa-riddle@uiowa.edu](mailto:melissa-riddle@uiowa.edu)



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