OCCR Quarterly

Oklahoma Central Cancer Registry Winter 2024

All photos used with permission from photographer, Meagan Carter. *Alaska Range, Denali*

Quality Assurance and Upcoming Audits

Our cooperative agreement with the CDC National Program of Cancer Registries (NPCR) requires that we conduct quality assurance (QA) activities every year to ensure we receive timely data of the highest quality from our facilities. Our team has been sending quarterly emails regarding compliance and will continue to do so; however, compliance is not just related to timely reporting. Compliance is three-fold: timeliness, completeness, and high-quality data. Now that the OCCR is fully staffed, we will continue to expand compliance past timeliness to include quality and completeness of reporting.

OCCR's team has completed several audits on several facilities over the last few years, however staff vacancies and workloads prevented us from accomplishing as many as we would have liked. While OCCR will continue to do a number of annual QA audits, we are currently in the process of contracting a vendor to provide external QA audits to provide feedback to facilities on their data quality and completeness. Our goal is to audit every reporting facility at least once within each five-year grant cycle. When QA audit results come back, Sandie Steen, OCCR's Education and Training Specialist will follow up and provide support and training to address any completeness and quality issues.

We sincerely thank you for partnering with us on the timely reporting of complete, high-quality data. When it is time for your facility to receive a QA audit we will reach out to your team with more details.

Meagan Carter, MS
OCCR Program Manager

Reminders for Text PE, Text X-ray/Scan and Text Remarks

Text fields are incredibly helpful in determining the most accurate cancer information for the data that we provide with your help to the CDC and NAACCR. NAACCR approved abbreviations may be used in all text fields and can be found in the NAACCR Data Standards and Data Dictionary. If no information is available for a specific text field, please document "No information available" which acknowledges the field and lets us know that we have all of the available cancer information for that section of the abstract.

Text PE must include:

- Date of first contact
- Date of diagnosis (if not clearly indicated elsewhere in the abstract) and diagnosing physician
- History of Presenting Illness (HPI), signs or symptoms prompting workup and/or the reason the patient presented for medical care.
- Race and ethnicity information when available
- Physician exam notes with date of exam and includes exams such as Digital Rectal Exam (DRE), LNs, etc[1].
- Treatment Plan
- Follow up exams including if the patient becomes disease free and/or has No Evidence of Disease (NED) on a later exam
- If no PE information available, that must be documented for example "No PE in patient record"

Text X-ray/Scan is the section of the abstract used to document all X-Rays, MRI, scans (CT, CAT, PET, etc) and other imaging examinations that provide information about cancer staging for the patient's specific cancer. Procedural information must be documented including:

- Date of procedure, type of procedure anatomical site of procedure, and include all relevant positive and negative findings with positive results listed first[1].
- Any x-ray or scan findings about primary site location, histology, tumor size and/or spread, lymph node involvement, and metastatic sites.

Text Remarks is an excellent place to document important abstract details that are not appropriate for other more specific fields. Text remarks can include:

- Reason for reporting a case seemingly not reportable[1]
- Reason for coding numerous fields as unknown[1]
- Unknown social security number
- Justification of override flags
- Second course treatment
- Recurrence information
- Date of death or patient deceased, date of death unknown

Sources

1. North American Association of Central Cancer Registries. 2018. NAACCR Data Standards and Data Dictionary: Data Descriptor Table.
   https://apps.naaccr.org/data-dictonary/data-dictionary/version=22/chapter-view/data-descriptor-table/
2. Registry Partners. October 2020. CTR Coding Break: Abstracting in Text
   https://drive.google.com/file/d/1WkR6qfqleo6PCathI7DoOZYF0mdMCddQ/view

Continued on page 3

Reminders for Text PE, Text X-ray/Scan and Text Remarks

Sources, continued from Page 2

3. James Steen, Sandie. September 2023. Oklahoma Central Cancer Registry Texting: CYA (Complete Your Abstract).

4. Maryland Central Cancer Registry. 2011. Appendix III: Text Fields: Guidance on Entering Text Into Specific Fields. https://health.maryland.gov/phpa/cancer/documents/appendix3_text.pdf

Alex Cousins, BS, ODS-C
Cancer Registry Consultant

Meagan Carter, MS, Alaska, Knik Glacier

Submission Schedule for Cancer Reporters

Date of First Contact:	Required to be Reported to OCCR in:
January 2023	July 2023
February 2023	August 2023
March 2023	September 2023
April 2023	October 2023
May 2023	November 2023
June 2023	December 2023
July 2023	January 2024
August 2023	February 2024
September 2023	March 2024
October 2023	April 2024
November 2023	May 2024
December 2023	June 2024

Timing for Submission of Abstracts with Treatment

In the last quarter of 2023, the Oklahoma Central Cancer Registry (OCCR) received several questions from reporting facilities regarding abstracts with treatment and when to submit them to the OCCR. The patient's treatment plan is key to knowing when to submit the abstract to the state. The abstractor should be familiar with the types of cancer-directed treatment performed at the reporting facility. At completion of the case, the abstractor should have a good idea of the treatment plan for the patient.

Abstracts should be submitted to the state within 180 days of the date of first contact when:

- The patient is diagnosed at your facility and all first course cancer-directed treatment will be performed elsewhere.
  OR
- The patient is diagnosed at your facility, and after a thorough review of the medical record, it is unknown where the patient will have cancer-directed treatment.
  OR
- All cancer-directed treatment planned at your facility has started within 180 days from the date of first contact.

Do not hold your cases until all cancer-directed treatment at your facility is complete. Length of cancer-directed treatment can vary by patient. Standard of care treatment guidelines are available. The National Comprehensive Cancer Network (NCCN) or the American Society of Clinical Oncology (ASCO) are the most widely recognized. However, each patient's cancer journey can be different. Treatment length can depend on the primary site, histology and behavior, the patient's willingness to undergo treatment, and how well treatment is tolerated to name a few reasons. This is why a thorough review of the medical record is necessary to help determine when a case is ready to be submitted. Do not hold your cases past the 180-day timeframe for pending treatment information from outside facilities. Document in text that the treatment modality is planned at XYZ facility and is unknown if performed.

Cases where all treatment modalities planned at your facility have not yet started should be held in your database as incomplete or in suspense. Reporting facilities that provide cancer-directed treatment should have a plan in place to review partially abstracted cases periodically for pending treatment planned at the reporting facility. This will allow the case to be completed at the earliest possible time. The case should be completed, and status changed to complete, or suspense flag removed as soon as the last planned treatment modality at your facility has started. This will allow the case to be included in the next batch of cases being sent to the state.

The OCCR recognizes that some cancers may have long treatment periods at facilities that provide comprehensive cancer care. For example, rectal cancer treatment can last a year or more if the patient receives neoadjuvant chemo-therapy and radiation therapy followed by surgical resection of the primary site followed by adjuvant chemotherapy. In cases like this, it may not be possible to submit the case within the 180-day timeframe according to the submission schedule. Reporting facilities should not have many cases that fall outside of the reporting guidelines. Most cases can be submitted within 180 days from the date of first contact.

Additionally, for facilities that perform cancer-directed treatment, abstracting cases prior to 180 days from the date of first contact may not allow enough time for all treatment to begin. As mentioned previously, please be sure to have a plan in place to review cases periodically for treatment according to the treatment plan. As always, please contact the OCCR with any questions.

Christy Dabbs, AA, ODS-C
OCCR Data Manager

Protecting Privacy

OCCR relies heavily on our facilities to provide us with accurate and concise information when reporting cancer cases. During this exchange of patient information, we often share protected health information (PHI).

There are several ways for reporters and the OCCR team to securely share PHI for cancer reporting and every effort must be made to protect the information that is provided to us. The best way would be to provide all pertinent information needed in a timely manner through a complete abstract in Rocky Mountain Cancer Data Systems (RMCDS) or Web Plus. Other ways we obtain information are through phone calls, fax, and secure email. Safeguards should be put into place when using these means of communication including:

- Awareness of your surroundings when communicating by phone.
- Using a fax cover sheet with a confidentiality statement when transmitting PHI.
- All emails should be sent securely.

The federal government has put strict guidelines into place to protect each of us. The Heath Insurance Portability and Accountability Act (HIPAA) was enacted into law in 1996. This federal law created national standards to protect PHI and includes hefty penalties when the law is not followed appropriately. The HIPAA Privacy Rule covers who are allowed to share PHI, and the HIPAA Security Rule gives us guidance of how the information should be shared. More information for professionals and HIPAA can be found here.

Privacy must be everyone's highest priority and every effort should be made to protect PHI. If you are unaware of your facility's secure email procedures or you do not have access, every effort should be made to reach out to your supervisor or IT department.

Lisa Fulkerson, RMA
Cancer Registry Consultant

KUDOS! WAY TO GO!

Congratulations!

PROPS! NAILED IT!

We have some exciting news to share about OCCR Physician and Treatment Center Consultant, Randi Spicer. Randi was one of 85 candidates that passed the fall 2023 exam to earn the Certified Tumor Registrar (CTR) credential. As it happens, her passing grade came just as the National Cancer Registrars Association (NCRA) announced that the CTR credential would be updated to Oncology Data Specialist-Certified effective January 1, 2024.

The OCCR applauds Randi for her dedication and congratulates her on her new credential.

RANDI SPICER, AAS, ODS-C

Leslie Dill
Cancer Registry Consultant

Appendiceal Mucinous Neoplasms: LAMN and HAMN

Appendiceal mucinous neoplasms (AMNs or, in some literature, MANs) are epithelial tumors of the appendix that produce extracellular mucin. Mucin is a protein made by cells that creates a thick fluid called mucus. These tumors are broadly divided into two main classifications: appendiceal mucinous neoplasms (AMNs) and mucinous adenocarcinomas.

AMNs and mucinous adenocarcinomas produce extracellular mucin that can lead to pseudomyxoma peritonei; however, the distinction between AMNs and mucinous adenocarcinomas lie in how these tumors behave.

Mucinous appendiceal neoplasms lack an infiltrative growth pattern, destructive invasion, or a stomal desmoplastic reaction. Although the tumor pushes outward into the muscularis mucosa, they are confined by the muscularis propria. These tumors are called low-grade appendiceal neoplasms (LAMN) if they have low-grade cytologic features; they are called high-grade appendiceal neoplasms (HAMN) if they have areas with high-grade cytologic features.[1]

Mucinous adenocarcinomas of the appendix are frankly invasive. They can be classified as well, moderately or poorly differentiated mucinous adenocarcinomas. The presence of signet ring cells automatically consigns the tumor to the poorly differentiated category. Mucinous adenocarcinomas are defined as invasive glands containing high-grade cytologic atypia and extracellular mucin making up >50% of the cross-sectional area of lesion under the microscope.[1]

These tumors all have one thing in common: they can perforate or rupture the appendix allowing extracellular mucin to accumulate in the peritoneal space causing pseudomyxoma peritonei (PMP). Pseudomyxoma peritonei is sometimes referred to as mucinous carcinoma peritonei. Historically, PMP was also known as “jelly belly”, disseminated peritoneal adenomucinosis (DPAM), peritoneal mucinous carcinomatosis (PMCA) or peritoneal mucinous carcinomatosis with signet ring cells. Regardless of the term used, it is important to remember that pseudomyxoma peritonei is a clinical term, not a histologic diagnosis.[3] This syndrome is characterized by the accumulation of mucinous, or gelatinous, ascites and mucinous implants on peritoneal surfaces. PMP has been further clarified by the World Health organization (WHO): low-grade mucinous carcinoma peritonei (MCP-L), synonymous with DPAM; high-grade mucinous carcinoma peritonei (MCP-H), synonymous with PMCA. A classification of MCP-H with the presence of signet ring cells is now noted as MCP-H-S and was previously known as PMCA-S.[4]

It is worth noting that almost all cases of PMP originate from the appendix, however PMP is also known to occur in the setting of other primaries, such as ovary or small bowel.

Primary appendiceal neoplasms are most often found incidentally. For example, in an appendectomy specimen following an episode of acute appendicitis. Tumors staged as Tis and T1 may be treated with appendectomy only if there are negative margins and there is no angiolymphatic invasion. T1 or T2 tumors with positive margins or angiolymphatic invasion should be considered for a right hemicolectomy. Regardless of the type of surgery, all patients should undergo exploratory examination of the abdomen to assess the presence or absence of peritoneal spread. This can be done at the time of appendectomy or hemicolectomy or separately.[4]

Select patients with metastatic spread to the peritoneum may be considered for cytoreductive surgery (CRS) and hypothermic intraperitoneal chemotherapy (HIPEC). It is now understood that an aggressive surgical approach in patients with metastatic disease confined to the peritoneum can result in long-term control and even cure in many patients.[2]

Presurgical evaluation of peritoneal involvement is recommended and can be done laparoscopically; the PCI (peritoneal carcinomatosis index) scoring system is used and quantifies the distribution of peritoneal spread in 13 regions of the abdomen and pelvis. Complete CRS is the removal of all visible disease found in the peritoneum or surrounding viscera and is noted as CC-0 or CC-1; for unresected disease, the size of individual tumors cannot be more than 2.5 mm. Incomplete CRS is noted as a CC-2 or CC-3.[4,5]

Continued on pages 7 and 8

Appendiceal Mucinous Neoplasms: LAMN and HAMN

Continued from page 6

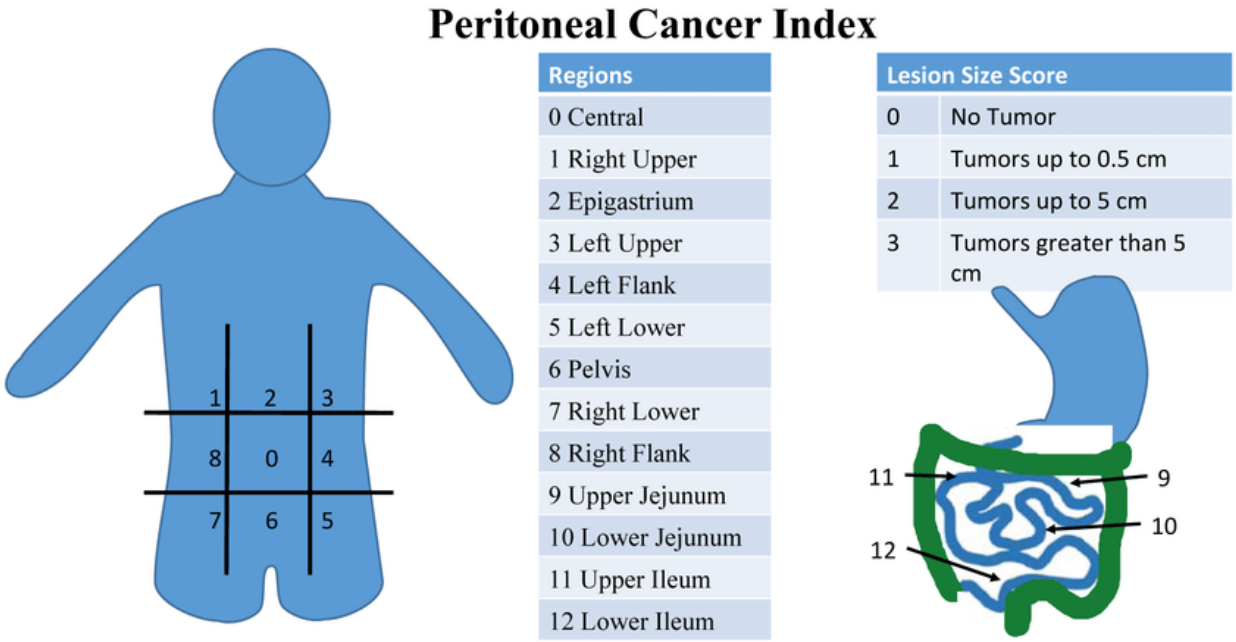

Figure 1: Peritoneal Cancer Index (PCI) scoring system.[5] PCI is a diagnostic and prognostic tool that is a sum of scores in thirteen abdominal regions. Each receives a score of 0-3 based on the largest tumor size in each region. Scores range from 0 to 39. Higher scores indicate more widespread and/or larger tumors in the peritoneal cavity.

Completeness of Cytoreduction Scores[5]	
Score	Size of largest post-surgery residual tumor
CC-0	No visible tumor
CC-1	Less than 0.25 cm
CC-2	Between 0.25 cm and 2.5 cm
CC-3	>2.5 cm or confluent

Table 1. CC is the completeness of cytoreduction score and indicates the size of the largest tumor that remains after cytoreductive surgery.

It is generally accepted that there is no role for systemic chemotherapy in LAMN and low-grade pseudomyxoma peritonei. For grade 2/grade 3 appendiceal mucinous neoplasms, systemic chemotherapy generally follows fluorouracil-based regimens, similar to those used for colorectal cancer.

LAMNs and HAMNs became reportable with cases diagnosed 1/1/2022; reporters should refer to the SEER Solid Tumor Rules, Colon chapter for assistance with coding these tumors. If you would like to know more about these tumors or have any questions, please do not hesitate to reach out to me.

References on page 8

Appendiceal Mucinous Neoplasms: LAMN and HAMN, cont.

References from page 7

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Meagan Carter, Alaska, Aurora

Case Reportability, Ambiguous Terms and Differential Diagnosis

Cases reportable to the OCCR include:

- patients newly diagnosed with cancer, clinically or pathologically;
- patients receiving first course cancer treatment;
- patients that present from an outside facility with a clinical diagnosis and are seeking tissue confirmation by biopsy;
- patients that have cancer previously diagnosed and treated elsewhere and present for diagnosis or treatment of recurrent or persistent disease;
- or patients who expire with active cancer at the reporting facility. Class of Case defines the facility's role in the patient's cancer diagnosis and treatment.

The OCCR Cancer Data Reporting Manual list reportable and non-reportable diseases on pages 30-33.

If a clinical diagnosis is made and is then proven to be benign by pathology, it becomes non-reportable.

Ambiguous terms are considered reportable when they are used in conjunction with the words malignant, cancer, carcinoma, sarcoma, etc. Ambiguous terms can be found on page 33 of the OCCR Cancer Data Reporting Manual or page 33 of STORE Manual 2023.

Examples Using Ambiguous Terms:

Do report – Mammogram report states breast mass is suspicious for malignancy. Suspicious for malignancy is reportable ambiguous terminology. Please note, BI-RADS terms are not considered diagnostic on their own. For example, BI-RADS 5, highly suggestive of malignancy, does not constitute a diagnosis.

Do report – Discharge summary final diagnosis states probable primary lung malignancy. Probable primary lung malignancy is reportable ambiguous terminology.

Do not report – An outpatient CT scan of the chest documents a right lower lobe lung nodule, possible malignancy. The patient has no other encounters with your facility. Possible is not a reportable ambiguous term.

Cytology plus ambiguous term:

If cytology is identified only with an ambiguous term, do not interpret it as a diagnosis of cancer. Abstract the case only if a positive biopsy or a physician's clinical impression of cancer supports the cytology findings.

Differential Diagnosis:

A differential diagnosis is made when a physician does not have enough information to assign a definitive diagnosis. **Only report cases with a differential diagnosis if all possible disease processes mentioned are reportable.**

Do not report – CT exam of the chest shows a nodule in the left lower lung. The radiologist report has a differential diagnosis of suspicious for lung neoplasm vs metastatic lung lesion. Neoplasm is not a reportable term therefore Not Reportable.

Do report – CT exam of the chest shows a nodule in the left lower lung. The radiologist report has a differential diagnosis of suspicious for lung cancer vs metastatic lung lesion. Both are reportable terms.

Do report – Pathology report of brain tissue states CNS lymphoma vs CNS metastasis from unknown primary. Both are reportable conditions.

Continued on page 10

Case Reportability, Ambiguous Terms and Differential Diagnosis

Continued from page 9

- **Do not** report – MRI of the left thigh says deep tissue mass consistent with atypical lipoma or liposarcoma. The patient does not return to your facility. Atypical lipoma is not a reportable condition.
- **Do not** report – Bone survey states patient has a solitary lesion in the right humerus compatible with a bone is land or solitary plasmacytoma. “Compatible” is a reportable ambiguous term, but a bone island is not a reportable condition.

If you have any questions about reportability, please contact your OCCR Cancer Registry Consultant. We are always happy to help.

STORE Manual 2023. (n.d.). https://www.facs.org/media/r0ajvh5j/store-manual-2023.pdf

Oklahoma Central Cancer Registry Cancer Data Reporting Manual. (n.d.). https://oklahoma.gov/content/dam/ok/en/health/health2/aem-documents/health-promotion/occr/forms/Cancer%20Data%20Reporting%20Manual.pdf

Randi Spicer, AAS,ODS-C
Cancer Registry Consultant

Meagan Carter, Bartlesville Pond, Reeds

Questions & Answers

Questions and Answers:

Q1. Is the following a reportable diagnosis and, if so, what are the correct primary site and histology codes? Patient was found to have an intradural extramedullary meningioma of the cervical spine on imaging.
A1. Intradural extramedullary meningiomas are located within the dura but outside of the spinal cord. Because it is within the dura of the cervical spine, it is a reportable diagnosis. Assign primary site code C70.1 (spinal meninges) and histology code M9530/3 (meningioma, NOS).

Q2. Is myxopapillary ependymoma of the spinal cord a reportable diagnosis? If so, what are the correct primary site and histology codes?
A2. Ependymoma is a type of primary central nervous system tumor that develops in the brain or spinal cord; therefore, it is a reportable diagnosis.
Myxopapillary ependymoma are a variant type of ependymoma that occurs predominantly in the filum terminale and/or conus medullaris; both the filum terminale and conus medullaris are coded to primary site code C72.0 (spinal cord). Assign histology code M9394/1 (myxopapillary ependymoma).
Note: *Nonmalignant primary intracranial and central nervous system tumors diagnosed on or after 1/1/2004 with an ICD-O-3 behavior code of /0 or /1 are reportable for the following sites: meninges (C70._), brain (C71._), spinal cord, cranial nerves and other parts of the central nervous system (C72._), pituitary gland (C75.1), craniopharyngeal duct (C75.2) and pineal gland (C75.3). See OCCR Cancer Data Reporting Manual pg. 31.*

Meagan Carter, Ice on the Pines

Q3. Is the following skin lesion reportable? Pathology report final diagnosis states, "atypical junction nevo-melanocytic proliferation consistent with early lentigo maligna (D03.39)."
A3. Beginning with cases diagnosed 1/1/2021 or after, early lentigo maligna is reportable. Lentigo maligna is a type of in situ melanoma that is characterized by a flat or slightly raised brown patch, similar to a freckle or age spot, with a smooth surface and an irregular shape. They are usually found on the faces of elderly people. Lentigo maligna grows slowly but can become lentigo maligna melanoma which is a type of invasive skin cancer that spreads aggressively.

Q4. Is pure LCIS (lobular carcinoma in situ) reportable?
A4. Per STORE 2023, pg. 46, "Lobular Carcinoma In Situ alone is not reportable to CoC. The decision not to collect LCIS was made to align STORE with the AJCC 8th Edition. Please see the AJCC 8th Edition for complete details. Please note: SEER and NPCR require reporting of LCIS. If LCIS is reportable for your state registry, follow your state registry requirements. Assign Class of Case according to the relationship between the patient and the reporting facility."
OCCR follows the reporting requirements as set forth by NPCR. ***Therefore, LCIS is still reportable to OCCR.*** *Assign class of case 34 or 36 as appropriate to the case; if you are not seeing the patient for initial diagnosis and/or first course of treatment, assign class of case 32 instead.*

Sandie James Steen, ODS-C
Education & Training Specialist

The Buzz Among Researchers

Registrars are often expected to provide a high level of accuracy and completeness with limited time and staffing. Often this expectation leaves little time for educational opportunities. To help with this, the OCCR provides a quarterly sampling of the most current published research articles that we feel may be of interest to community registrars.

Potential new treatment for pulmonary neuroendocrine tumors

Date: December 11, 2023
Source: Hubrecht Institute

The Organoid Group (Hubrecht Institute) and the Rare Cancers Genomics Team (IARC/WHO) found a way to grow samples of different types of neuroendocrine tumors (NETs) in the lab. While generating their new model, the researchers discovered that some pulmonary NETs need the protein EGF to be able to grow. These types of tumors may therefore be treatable using inhibitors of the EGF receptor. The results were published in *Cancer Cell* on 11 December 2023.

Neuroendocrine tumors

Neuroendocrine tumors (NETs) are relatively rare tumors that can be slow growing.
However, some NETs can be aggressive and hard to treat. It is not yet possible to predict which tumors will become aggressive.
There are very few models to study NETs in the lab, which limits research into this type of tumor.

New disease model

Researchers from the Organoid Group (Hubrecht Institute) and the Rare Cancers Genomics Team (IARC/WHO) therefore set out to develop new models to study NETs.
They derived cells from patients with NETs and were able to culture them into 3D structures called organoids.
These organoids mimic the behavior of actual NETs and can therefore be used to study this type of tumor in the lab.
The new model is the first organoid model of the disease.

Growth factor

While generating the organoids, the researchers found that some pulmonary NETs need a protein called the Epidermal Growth Factor (EGF) to grow.
"If we inhibit the receptor for EGF, some organoids die. Apparently, these organoids are dependent on EGF for their survival," says Talya Dayton, co-first author on the paper published in Cancer Cell.
"We need further research to confirm our findings, but this may indicate that patients with EGF-dependent NETs could be treated with inhibitors of the EGF receptor." Inhibitors of the EGF receptor are already a course of treatment for other types of tumors.

Aggressive tumors

Tumors are usually thought to be independent of growth factors.
That some NETs turn out to be dependent on the growth factor EGF is therefore surprising.
"We think that their EGF-dependence might explain, in part, why some of these tumors grow slowly. We also think this might mean that one of the ways in which NETs can become aggressive is by becoming growth-factor independent. If they no longer need the growth factor, their growth may accelerate" Dayton explains.

Potential new therapy
The newly developed model for NETs provides a new way to study the disease in the lab. Dayton: "This allows us and other scientists to understand the biology of these tumors so we can hopefully find effective therapies." Although further research is needed, the model already points to a new route of treatment for patients with pulmonary NETs.

Continued on page 13

The Buzz Among Researchers, continued

Continued from page 12

Hubrecht Institute. "Potential new treatment for pulmonary neuroendocrine tumors." ScienceDaily. ScienceDaily, 11 December 2023. <www.sciencedaily.com/releases/2023/12/231211114511.htm>.

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2024 NCRA Annual Conference (ncra-usa.org)

2024 National Conferences

https://www.naaccr24boise.org

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