

# Effective Practices in **PANCREATIC CANCER** Programs



Association of Community Cancer Centers



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# BOLDER BRIGHTER BETTER...

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ACCC  
Association of Community Cancer Centers

40  
YEARS STRONG

Resources and tools for the multidisciplinary team



# Highlights of ACCC's Pancreatic Cancer Survey

About 45,000 people in the U.S. are diagnosed annually with pancreatic cancer; the disease is the fourth leading cause of cancer-related deaths. Despite the high numbers and devastating toll of the disease on patients and their families, practice patterns and resources for patients with pancreatic cancer are not well established. In 2013 ACCC conducted a survey to identify:

- Barriers to caring for pancreatic cancer patients
- Gaps in provider knowledge and resources about pancreatic cancer
- Effective practices and components of strong pancreatic cancer programs
- Community Resource Centers for pancreatic cancer.

This publication describes the information gathered from this survey.

## Survey Results

A total of 104 survey responses were returned. The majority of respondents were social workers (26 percent), oncology nurses (24 percent), and dietitians (20 percent) in hospital-based and out-patient cancer centers. Ten percent were patient navigators. Other team members included: practice managers or practice administrators (8 percent), cancer program administrators (4 percent), medical oncologists (4 percent), palliative care specialists (2 percent), and hematologic oncologists (2 percent). More than 60 percent of survey respondents reported seeing from 21 to 100 patients with pancreatic cancer each year.

Findings showed that a strong community-based pancreatic cancer program includes a multidisciplinary team and the presence of tumor boards, an engaged support staff (nurses, navigators, and social workers), and expert physicians, as well as access to clinical trials and financial assistance programs. Seventy-six percent of respondents stated that pancreatic cancer cases are reviewed in a multidisciplinary manner in their cancer program. Of those centers using a multidisciplinary team approach to treating pancreatic cancer patients, the team included a medical oncologist (96 percent); radiation oncologist (89 percent); oncology nurse (79 percent); and pathologist (77 percent).

The National Comprehensive Cancer Network (NCCN) Clinical Practice Guidelines for pancreatic cancer are the most used guidelines, followed by the American Society of Clinical Oncology (ASCO) guidelines. Most respondents use pancreatic cancer resources and tools from the American Cancer Society and the National Cancer Institute, followed by PanCAN, NCCN, and ASCO.

## Challenges & Barriers

The biggest challenge (56 percent) facing survey respondents is the patient's own structural, financial, and/or personal barriers, such as transportation or insurance issues, followed by managing transitions of care between numerous healthcare settings (50 percent). Additional challenges for the cancer care team in treating and supporting patients with pancreatic cancer and their families

included keeping current on the latest treatment modalities and the lack of psychosocial services and/or distress management programs for patients. A few respondents noted the lack of affordable nutrition counseling and overworked nurse navigators who have multiple roles within the community-based cancer program setting.

Time was the overwhelming barrier to learning and change as noted by 81 percent of respondents. Lack of support, such as financial and managerial, was noted by 44 percent. "Other" barriers cited by respondents were lack of staff and new and complicated electronic health records.

## Additional Education Needed

Respondents indicated that additional educational resources and tools that would be beneficial include patient brochures, an anatomical picture to illustrate the location of the disease to patients, and an assessment and tracking tool for newly diagnosed patients. Survey respondents also requested additional education on treatment options and treatment planning for pancreatic cancer patients. When asked to rank educational topics they viewed as essential in terms of the benefit they would receive from additional education, respondents are seeking additional information on:

- Treatment planning for resectable disease (60 percent)
- Neoadjuvant treatment options (51 percent)
- Financial assistance (50 percent)
- End-of-life care (48 percent)
- Palliative care (45 percent)
- Classification and staging (43 percent)
- Home/community support during treatment or post-operative care (41 percent).

## Community Resource Centers

Through survey responses, ACCC identified five member programs with experience and expertise in treating patients with pancreatic cancer. In this publication, these programs share practical strategies and insight into improving the delivery of quality care to patients with pancreatic cancer and their families. These programs will also serve as Community Resource Centers for ACCC's "Improving Quality Care in Pancreatic Cancer" education project, answering questions and providing guidance to cancer programs with less experience in treating patients with pancreatic cancer. Go to [www.accc-cancer.org/CRC](http://www.accc-cancer.org/CRC) to contact any of these programs.

- Winthrop-University Hospital, Institute for Cancer Care, Mineola, N.Y.
- Maine Medical Center Cancer Institute, Portland, Maine
- Kellogg Cancer Center, NorthShore University Health System, Evanston, Ill.
- The Virginia G. Piper Cancer Center at Scottsdale Healthcare, Scottsdale, Ariz.
- Winship Cancer Institute of Emory University, Atlanta, Ga.



# NAVIGATION IS KEY

## Winthrop-University Hospital, Institute for Cancer Care

Mineola, N.Y.

A strong community-based pancreatic cancer program includes a multidisciplinary team, as well as tumor boards, expert physicians, and an engaged support staff. The Winthrop-University Hospital Pancreas Program in Mineola, N.Y., has all that and more.

Recognized as a Center of Excellence by the American College of Surgeons Commission on Cancer, multidisciplinary communication underpins state-of-the-art technologies and strong research affiliations at the Winthrop-University Hospital Pancreas Program. Weekly tumor conferences bring the varied perspectives of medical and radiation oncologists, surgeons, advanced endoscopists, interventional and diagnostic radiologists, nurses, nutritionists, pathologists, and nurse navigators to discuss and direct a treatment plan tailored to each patient with pancreatic cancer.

“Regular open communication keeps the conversation and collaboration going among the disciplines. Collaborative care helps us erode the fatalism that is so commonly expressed about patients with pancreatic cancer,” said Christine Guarnieri, RN-BC, MSN, OCN, nurse navigator, colorectal/gastrointestinal and head/neck cancers.

### Navigation is Key

**With her advanced training,** Guarnieri is able to translate complex medical information for her patients to make the cancer experience understandable and manageable. She travels through the system with the patient, coordinating care. She likens her role as nurse navigator to the hub of a wheel.

“I’m in the center with the patient, sharing information with them, as well as keeping conversations going among specialties. My responsibility is to make sure everybody is on the same page,” said Guarnieri. She communicates with the entire multidisciplinary team, including genetics, pathology, nutrition, and social work, and also keeps outside physicians, such as the patient’s primary care physician or cardiologist, in the loop.

Guarnieri builds a bond with her patients early on. She is there with the patient at diagnosis and when the physician leaves the room. “When we first meet, patients may say this [diagnosis] is a death sentence. I answer that each patient responds differently to surgery, chemotherapy, and radiation. It’s not how much time you have left, but what you do with your time. I help patients define what is most important in their lives and what we can do on a daily basis in the time we do have.”

As treatment progresses, Guarnieri will have multiple conversations with each patient about his or her present state of physical and emotional health. If patients are doing well, she may speak with them once a week. When treatments fail or become more challenging, those conversations can increase up to three or four times per week. Guarnieri’s emphasis is on how best to help each patient maintain a good quality of life, so she pays careful attention to her patients’ psychosocial and nutritional health, as well as their physical health. “We want the patient to have the best possible quality of life. Our goal is to maximize outcomes for each patient and make pancreatic cancer a controllable illness,” she said.

Guarnieri, in collaboration with other oncology nurse navigators, developed a tool to quantify the cancer patient’s satisfaction. The tool is used to assess how navigation services helped patients in their overall cancer journey. Some sample questions from the survey evaluate if the patient received navigation services in a timely manner, if intervention by the navigator was helpful, if the connection with the navigator improved the patient’s overall cancer care experience at Winthrop, and if the navigation resource helped keep them from seeking care elsewhere. The tool is available online at [www.accc-cancer.org/pancreatic](http://www.accc-cancer.org/pancreatic).

## Access to Clinical Trials & Leaders with Specialized Expertise

**Community cancer programs are challenged** to keep up with the availability of clinical trials for patients with pancreatic cancer. Winthrop, a 591-bed teaching hospital, has an active cancer clinical trials program that offers a broad array of options to patients with cancer, through its affiliations with the Southwest Oncology Group (SWOG) of the new National Cancer Trials Network (NCTN), Gynecologic Oncology Group, and the CTSU (Clinical Trials Support Unit). At weekly tumor boards, the multidisciplinary team reviews those clinical trials most appropriate for its patients with pancreatic cancer.

Committed to research, as well as to medical education, the hospital is a clinical campus of Stony Brook University School of Medicine. Winthrop also has research affiliations with Cold Spring Harbor Laboratory and Roswell Park Cancer Institute.

Although access to clinical trials is important to the success of any pancreatic cancer program, physician leaders with specialized expertise in treating gastrointestinal (GI) and hepatobiliary cancers are critical to a program of excellence. Thanks to a strong commitment by hospital administration to recruit top physicians to its cancer program, Winthrop-University Hospital saw its surgical pancreatic cancer population jump from 4 cases in 2012 to 51 over the last nine months, when surgical oncologist John Allendorf, MD, joined the team. Previously at Columbia University Medical Center, Dr. Allendorf has pioneered several robotic and minimally invasive treatments for patients with pancreatic cancer who were previously thought to be untreatable. He became the driving force behind a new and streamlined pancreatic cancer program that expanded the range of treatment options the program offers patients.



**Guarnieri, in collaboration with other oncology nurse navigators, developed a tool to quantify the cancer patient's satisfaction.**

Today Dr. Allendorf works closely with Stavros Stavropoulos, MD, director of Endoscopy and director of the program in Advanced GI Endoscopy. Stavropoulos and his team offer extensive experience with a number of innovative procedures, including endoscopic ultrasound (EUS)-guided biliary drainage (EGBD), which can spare certain patients from the need for percutaneous drainage and external drains and bags. Another integral component of this program is driven by the medical oncology team, which includes Alexander Hindenburg, MD, FACP, attending physician in the Division of Oncology and Hematology. This team offers patients state-of-the-art chemotherapeutic and targeted treatments that are individualized for each patient, providing patient-centered care. Drs. Allendorf, Stavropoulos, and Hindenburg embrace the theory behind multidisciplinary communication, as well as the significant benefit that navigation brings to the patient.

## Patient Finances & Insurance

**An enormous challenge facing many cancer patients,** including those with pancreatic cancer, is their own financial and/or personal barriers, such as transportation or insurance issues. Winthrop-University Hospital has a financial assistance program located conveniently in an office at the infusion center. Social workers, as well as patient navigators at Winthrop-University Hospital Pancreas Program, ease patient concerns about transportation and insurance.

"As a nurse, I wear many hats," said nurse navigator Guarnieri. She helps patients overcome emotional, social, and clinical barriers, as well as talk about transportation and insurance issues, and makes referrals as needed. Over the last four months, she has fielded many more questions from patients about insurance changes. "I always tell patients if I don't know the answer to a specific [insurance] question, I will find the answer and together we will fix the issue. Having a cancer diagnosis is stressful enough. If I can alleviate some of the paperwork or phone calls for patients, I am happy to do so."

Guarnieri notes that the increased paperwork and letter writing by nurses and oncologists to deal with chemotherapy and diagnostic testing insurance claim denials threaten to cut into the time they can spend with patients.



*Members of the HBP (hepatobiliary/pancreatic) multidisciplinary cancer conference discuss a patient's current health status, recent diagnostic imaging, and future recommendations for treatment.*

# COLLABORATIVE & COMPASSIONATE CARE

## Maine Medical Center Cancer Institute

### Portland, Maine

Maine Medical Center Cancer Institute provides comprehensive, multidisciplinary care for patients with pancreatic cancer through the Pancreaticobiliary Center within the Maine Digestive Health Center. No other hospital in Maine offers this depth and breadth of clinical expertise and experience in treating GI cancers. Maine Medical Center is the only hospital in the state, for example, with several fellowship-trained surgical oncologists, three board-certified colorectal surgeons, and a group of highly trained GI endoscopy specialists. From January 2012 to December 2013, Maine Digestive Health Center saw 171 patients with pancreatic cancer.

“We are the go-to people in the state for care of patients with pancreatic cancer, because we have such a strong team of expert physicians,” said Gina M. Zilio-Smith, BSN, RN, OCN, CHPN, oncology nurse navigator, upper GI, at Maine Medical Center.

### Coordinated, Collaborative & Compassionate Care

**Zilio-Smith credits strong physician champions** for the success of the pancreatic cancer program. Over the last several years, surgical oncologist Lisa A. Rutstein, MD, FACS, and gastroenterologist Douglas A. Howell, MD, have encouraged “respectful collaboration” among all the appropriate specialists involved in the evaluation and management of pancreatic cancer. These specialists have worked to streamline access to a range of advanced diagnostic and treatment services and to develop and refine evidence-based, best-practice protocols to ensure that patient care is consistent and well-coordinated.

Today, eight site-specific nurse navigators help cancer patients during the diagnosis and staging process by coordinating their care at Maine Medical Center. Zilio-Smith provides information to help patients with pancreatic cancer make healthcare decisions. She assures patients that they are not alone and that she is available at every step in the process from diagnosis to resolution. Her main role is to assess for barriers to safe and expeditious care, offering the support of social work, nutrition, psychiatry, American Cancer Society Navigation, and the Cancer Risk and Prevention Clinic at Maine Medical Center Cancer Institute. As part of the initial discussion, she takes each patient’s family history. If patients are concerned about genetic risk for pancreatic cancer in other family members, she can refer them to the Cancer Risk and Prevention Clinic. For some, a thorough risk assessment and genetic counseling provide enough information to make a plan for lowering other family members’ risk of cancer. Abnormal genes may cause as many as 10 percent of pancreatic cancers and can cause familial pancreatitis as well.



*Nurse navigators provide annual education and outreach to their colleagues and the general public. Zilio-Smith is shown here presenting education, support, and literature for November’s Pancreas Cancer Awareness Month.*





**With certifications in hospice and palliative care, as well as oncology nursing, Zilio-Smith understands the unique needs of patients with pancreatic cancer...**

Patients with pancreatic cancer often arrive at the hospital jaundiced, extremely ill, and worried. When patients come in for diagnostics, they are encouraged to stay overnight for staging, which usually includes tissue analysis, a highly specific pancreas CT scan, an endoscopic ultrasound, and a diagnostic laparoscopy with the surgical oncologist. These exams can be completed in 48 hours. During this time, Zilio-Smith develops a plan of care that includes the date and time of an outpatient medical oncologist consult within the patient's local community, literature about their disease, contact information, and assurances that patients can call the nurse navigator with any questions or concerns.

With certifications in hospice and palliative care, as well as oncology nursing, Zilio-Smith understands the unique needs of patients with pancreatic cancer and the family dynamics of dealing with the disease. "Grief starts the moment of diagnosis," she said. "Patients grieve about what might be or what might not be. I have conversations that are frank and honest, realistic but not completely without hope. Cancer has a way of taking control away from patients and families. I try to help them put this in perspective and provide them with education and support. Sometimes it's the not knowing that is the hardest."

For those patients who may have an aborted Whipple procedure (pancreatoduodenectomy) or find surgery is not an option, Zilio-Smith explains the details of palliative care. She offers patients a consult with the medical center's highly trained team of pain and palliative care physicians, who can guide them through the process, establish goals, and bring the family on board.

Patients receive an American Cancer Society accordion file "Health Manager" to help them better manage their treatment schedules and keep all documentation in one place. A binder of supportive information is available to caregivers as well. Through a grant, the team has also developed a binder book for patients specific to the Whipple procedure. This binder includes a detailed outline of "before, day of, and after your surgery," as well as information about what to expect during hospitalization, members of the treatment team, pain management, nutrition, rehabilitation, and leaving the hospital. This binder

supplements the extensive tutorial visit that the nurse practitioner provides the patient and family prior to surgery. This tool is available online at [www.cancer-org/pancreatic](http://www.cancer-org/pancreatic).

### **An Open Door Policy to Navigation**

**Maine is one of the most rural states in the nation**, and vast distances separate the northern part of the state from the southern. Some patients have never visited the city of Portland. Some live in the woods or on islands; others in small cabins and campers, said Zilio-Smith. Many cannot afford the gas to drive the long distances from their homes to Maine Medical Center, and others cannot afford a hotel room for family members. Social workers at Maine Medical Center and an American Cancer Society navigator work with the Ronald McDonald House, Gary's House, Brackett House, and a number of local hotels to offer low-cost accommodations and discounted family rates.

With the many challenges particular to Maine's rural residents, Zilio-Smith advocates an "open door policy" to navigation with her pancreatic cancer patients. "We try to keep people in their community if that is in their best interest and helps their quality of life," she said. "An open door policy to navigation means that most of my work as nurse navigator is in the outpatient world. Surgical Oncology and I work closely with medical and radiation oncologists and even rehab in local communities. When these local physicians take the reins, I am still never far from the action. I remain with patients from diagnosis through resolution—whatever that resolution is, and I encourage patients and their families to call me anytime."

Zilio-Smith follows her neoadjuvant patients as they move to Maine Medical Center's collaborating partners, including the Cancer Care Center of York County for radiation treatment and Maine Center for Cancer Medicine, a private, regional medical oncology group, for chemotherapy. To make sure no patient falls through the cracks, Zilio-Smith calls community medical oncologists every few weeks and collaborates with regional centers in northern New England through their navigators, oncology nurses, and medical oncologists to check patient treatment status. Regular updates allow her to arrange for timely restaging and follow up with the surgeon. Finally, she assures that all pertinent documentation from Maine Medical Center is sent to the appropriate off-site physicians who may not have access to the Maine Health EPIC electronic health record system.





# A TEAM OF EXPERTS

## Kellogg Cancer Center, NorthShore University Health System

Evanston, Ill.

A high level of collaborative expertise and standardization of care brings better outcomes. That's the clinical philosophy of the Pancreatic Cancer Program at the Kellogg Cancer Center at NorthShore University Health System (NorthShore), based in Evanston, Ill. Designated by the National Cancer Institute as one of only 50 Community Clinical Oncology Programs, Kellogg Cancer Center is one of the busiest clinical programs in the state of Illinois and the Midwest. More than 130 patients with pancreatic cancer were seen in 2013. NorthShore is a four-hospital system in Chicago's northern suburbs, with NorthShore Evanston Hospital as the flagship. Kellogg Cancer Center has locations at three of its hospitals.

### Putting Together a Team of Experts

"Pancreatic cancer is a complicated cancer with such a low survival rate that you need a team with focused and differentiated expertise," said Mark S. Talamonti, MD, chairman of the Department of Surgery and the Stanton and Margaret Rogers Palmer Chair of Surgery at NorthShore. "For pancreatic cancer programs to be excellent, you can't have providers who dabble in the disease. We've concentrated our expertise and our focus on a few experts who see a large number of patients. That theme is true, whether we are talking about interventional GI, surgical oncology, or medical oncology."

Physician leaders in the Pancreatic Cancer Program include Talamonti, as well as Robert Marsh, MD, director, Gastrointestinal (GI) Oncology, and gastroenterologist Mick S. Meiselman, MD, chief, Advanced Therapeutic Endoscopy Section. These physicians work with a dynamic team of oncology nurses, a GI-cancer nurse navigator, and a surgical nurse navigator, who turn the concept of standardization into a day-to-day reality.

Evidence-based clinical pathways at NorthShore help ensure that there is no variation in the way patients with pancreatic cancer are cared for—from how surgery is performed in the operating room to how patients are treated post-operatively to how and when patients receive chemotherapy and fluid resuscitation. The team uses stringent categorization standards, so that patients who are surgical candidates are offered surgery and patients who are not surgical candidates do not go through needless operations.

The Whipple procedure is a difficult and demanding operation for both the patient undergoing surgery and the surgeon. "Specialization and standardization have made the biggest, most formidable surgical procedure in all of abdominal surgery better for patients," said Talamonti, who performs about 60 Whipple procedures each year. Only he and surgeon Marshall Baker, MD, MBA, perform this surgery at NorthShore, working closely with the same five nurses. On the floor, a standardized clinical pathway specifically for these patients helps accelerate recovery. "We standardize the way we do things, preoperatively, in surgery, and post-operatively in recovery. The same way—every time. Predictable and controllable," said Talamonti.

The hallmark of a successful pancreatic cancer program is a multidisciplinary, collaborative approach to decision making. Although robust discussions take place during weekly tumor board meetings at NorthShore, a better approach, said Talamonti, is to put physician team members together in the same space with the patient.

"Tumor boards are not real-time for the patient," said Talamonti. At NorthShore, "we're in the workroom with the residents, nurses, and specialists from all the relevant disciplines. We're looking at the scans together, making multidisciplinary decisions with the gastroenterologist and the medical oncologist, and doing so at the same time that the patient is in the room with us. That's what sets us apart from other programs." NorthShore integrates physicians from surgery, gastroenterology, and medical oncology so that patients can see all the physicians at one appointment in which a course of action is defined.



The hallmark of a successful pancreatic cancer program is a multidisciplinary, collaborative approach to decision making.

### Collecting Data to Predict Success

NorthShore has taken the power of the electronic medical record (EMR) to a new level, turning patient records into an actual research tool to help predict success or failure in treating patients with pancreatic cancer. More than 300 discrete data elements are collected in both the ambulatory and inpatient settings for each patient with pancreatic cancer seen in NorthShore's multidisciplinary clinic. Using the EPIC EMR system, NorthShore surgeons enter variables related to estimated blood loss in the operating room, operating room time, length of stay in the hospital, and complication rates after surgery, while the medical oncologists enter such variables as preoperative neoadjuvant therapies, dose escalations or reductions, and treatment delays, and take a thorough family history.

In effect, every data element important for a pancreatic cancer surgeon or a pancreatic cancer medical oncologist to know is collected, according to Talamonti. As each event is documented in the medical record, discrete elements are sent to a data warehouse housed at NorthShore's Center for Clinical and Research Informatics. The pancreatic cancer data can be used for research to determine the best treatment options for individual patients.

"I can call up our research coordinator and ask of the last 200 pancreatic resections we have done, how many were on protocols and how many were off protocols, how many are alive with the disease and how many have died from the disease. The ability to incorporate real-time research data into the day-to-day workflows of a busy surgeon or medical oncologist is setting the standard for clinical informatics," said Talamonti.

Nurse navigator for the GI Oncology program Margaret Whalen, RN; advanced nurse practitioner Colleen Temple, APRN; and research nurse Susan Jane Stocker, LPN, BLS, CCRP; maintain integrity and completeness of the database. One of these three nurses makes sure that these patients' data stay in the system when patients leave the hospital in order to do long-term follow-up closer to home.

### Access to Clinical Trials

The team at NorthShore is committed to enrolling patients with pancreatic cancer on clinical trials, even though some patients newly diagnosed with pancreatic cancer may believe they require immediate surgery and don't have the will or the time to follow through with a research protocol, Talamonti noted. "The reality is these patients need to be staged appropriately with modern high-quality, three-dimensional imaging, and if eligible for a clinical protocol, be placed on that trial, especially one of our neoadjuvant protocols, where chemotherapy and/or radiation are given before the surgery," said Talamonti.

NorthShore offers a comprehensive range of regional and national trials. Talamonti has served as the principal investigator or co-investigator on two Intergroup Trials examining the role of combined chemotherapy with external beam radiation therapy as neoadjuvant strategies prior to Whipple procedures for potentially resectable pancreatic cancer. His colleague Dr. Marsh is currently leading a multi-institutional clinical trial using FOLFIRINOX-based therapy for borderline resectable cancers.



Left: Mark S. Talamonti, MD, is chairman of the Department of Surgery at NorthShore University Health System and heads NorthShore's Pancreatic Cancer Program.

Below: Dr. Talamonti leads a tour of a surgical unit at NorthShore Evanston Hospital.



# ACCESS TO CLINICAL TRIALS

## Winship Cancer Institute of Emory University

Atlanta, Ga.

Winship Cancer Institute of Emory University is Georgia's only National Cancer Institute-Designated Cancer Center and serves as the coordinating center for cancer research and care throughout Emory University. A highly skilled multidisciplinary team facilitates treatment for about 250 to 300 patients with pancreatic cancer each year. That team includes more than 20 physicians who practice within this disease site, as well as a group of experienced nurses, nurse practitioners, residents, and support care professionals that include nurse navigators, dietitians, a psychiatrist, rehabilitation professionals, financial counselors, chaplains, and social workers.

"The multidisciplinary team meets at our GI tumor board, where our team of specialists can review imaging and discuss complex patient cases. A GI tumor board, in addition to complete and precise data within the EMR, is one of the best ways to effectively communicate a patient's plan of care," said Bonnie Josaphs, BSN, RN, OCN, GI oncology nurse navigator.

### Access to Clinical Trials

After a referral from the hospital or a community physician, and even before the patient walks through the door of the Winship Cancer Institute, Josaphs reviews GI oncology charts to navigate patients to the appropriate physicians and alert the team to potential clinical trial patients. She tries her best to make sure patients see the appropriate professionals in a timely manner. "Recognizing and coordinating multidisciplinary appointments help to expedite patient care," said Josaphs, who is often the first clinical team member that patients with pancreatic cancer talk to after their referral to Winship.

Referrals may come from community physicians who send patients to Winship Cancer Institute for second opinions and for specialized services, such as state-of-the-art liver treatment and access to clinical trials. Winship also has a specialized clinic for patients with neuroendocrine tumors, which are less commonly treated within the community due to the rare nature of the disease. Patients receive same-day evaluation from medical, surgical, and interventional oncology, in effect a mini-tumor board, to formulate a multidisciplinary treatment plan.

Winship encourages second opinions for patients. "Although we offer many options, we are not all inclusive

for every treatment offered for pancreatic cancer," said Josaphs. "If a patient would like a second opinion, we encourage them to look at other NCI-designated institutions to empower their own decision making—to take that opinion back to their local community or join one of our clinical trials."

Winship offers trials for patients with pancreatic cancer through all stages of the disease, from those newly diagnosed to those who may have progressed through standard of care. "We are particularly pleased about offering stereotactic body radiation therapy [SBRT] to pancreatic tumors in our clinical trial for borderline resectable disease. It is exciting to think that through our research we could one day be a part of changing the standard of care for this disease," said Josaphs.

Initiatives such as the Georgia Center for Oncology Research and Education (Georgia CORE) work to expand availability of clinical research throughout the state. Collaborative research initiatives with partners such as Georgia Tech, the U.S. Department of Defense, and the American Cancer Society fuel groundbreaking bench-to-bedside scientific work.



Someone [on staff]  
is available 24/7 for  
symptom management.

## A Strong Support Team

As GI oncology nurse navigator, Josaphs guides and supports patients and families through the treatment process. “I can meet with a newly diagnosed pancreatic cancer patient on their first visit to the clinic. I am their global positioning system, getting patients where they need to be and expediting a plan of care. My most important role is patient advocacy and education, informing patients about the many support services available to them.”

Winship’s support programs treat mind, body, and spirit, and are designed to help patients and families before, during, and after cancer treatment. Patients have access to a survivorship clinic, lymphedema clinic, palliative care, and rehabilitative medicine. Winship’s supportive care team includes nurse navigators, dietitians, a psychiatrist, rehabilitation professionals, financial counselors, chaplains, and social workers.

Social worker Maggie K. Hughes, LMSW, meets with every pancreatic cancer patient on their first day of chemotherapy, which for these patients can last upwards of six hours. She will do a full psychosocial assessment, checking the patient’s mental health history, advising the patient about free counseling services, or making a referral to the psychiatrist, if needed. She’s also there to advise patients about practical resources, whether they have difficulty getting transportation to treatment or affording medication co-pays. She encourages patients to use the patient portal on Winship Cancer Institute’s website, where patients can check their most recent lab and access their newest clinical information.



Winship’s support programs treat mind, body, and spirit, and are designed to help patients and families before, during, and after cancer treatment.

Hughes leads the only pancreatic cancer support group in Georgia. Participants range from patients just a week into treatment to a 12-year survivor. In this open monthly forum at the Winship Cancer Institute, discussions include the side effects of chemotherapy and digestive and eating problems, as well as the more difficult issues of depression and death. The group has been going strong for more than seven years.

The Winship Peer Partners Program is one of the many cancer survivorship programs available to pancreatic cancer patients. Cancer survivors are trained to talk with newly diagnosed patients, and the program matches cancer survivors and caregivers with cancer patients and caregivers dealing with a similar diagnosis of cancer. “We connect patients to patients,” Hughes said. “If a patient wants to meet a man in his forties who was recently diagnosed with pancreatic cancer and on a similar treatment, that person may already be in our database. We can match patients one on one with someone they can talk to over the phone. Patients think it’s wonderful.”

Patients can receive a full range of educational materials from the Pancreatic Cancer Action Network, the National Cancer Institute, and customized units, as needed, from the Krames StayWell educational system, such as management of nausea, for example. As important as these materials are, “it’s also important for patients to know who to call when they have questions, especially if they are having symptoms,” said navigator Josaphs. Although she can be the point person, Winship has a detailed protocol in place to help patients find the right staff professional quickly to answer their questions.

“Someone is available 24/7 for symptom management. We never want our patients to feel alone,” said Josaphs.



Above: Winship’s core values are prominently displayed on the stair tower of the LEED-certified building. They serve as basic tenets of behavior for all faculty and staff.



Left: Bassel El-Rayes, MD, associate professor of Hematology and Oncology, director of Winship’s Gastrointestinal Oncology Program, and associate cancer center director for Clinical Research, mentors medical residents evaluating complex patient cases as part of an academic teaching facility.

# NEW BEDSIDE DRUG THERAPIES

## The Virginia G. Piper Cancer Center at Scottsdale Healthcare

Scottsdale, Ariz.

The Virginia G. Piper Cancer Center at Scottsdale Healthcare sets its pancreatic cancer program apart through clinical trials. A partnership with the Translational Genomic Research Institute (TGen) has helped to accelerate bench research and to build a national reputation as the place for development of new bedside drug therapies for patients with pancreatic cancer. The clinical trials team is led by well-known cancer researcher Daniel D. Von Hoff, MD, who recruited a number of other outstanding physicians with expertise in pancreatic cancer, including Ramesh Ramanathan, MD.



**Although patients may join a clinical trial at any point in the treatment process, entering patients upon diagnosis is the preference...**

“Most pancreatic cancer patients that come to the Virginia G. Piper Cancer Center are eager to join a clinical trial, because it offers the best options for cutting-edge drug therapies,” said Molly Downhour, MHA, BSN, OCN, director, Virginia G. Piper Cancer Center Clinical Trials. Her advice for community-based programs without a world-renowned researcher like Von Hoff? To boost access to clinical trials, she suggests looking to the Pancreatic Cancer Research Team (PCRT), a consortium dedicated to offering pancreatic clinical trials to sites who share the vision to bring new advances to pancreatic cancer patients.

Although patients may join a clinical trial at any point in the treatment process, entering patients upon diagnosis is the preference at the Virginia G. Piper Cancer Center. At the initial consult with the physician and pancreatic cancer nurse coordinator, patients are evaluated for participation in a clinical trial. Once on the trial, one of six experienced research nurses oversees the care of the patient along with the physician investigators.

Downhour’s team has written a number of cancer research grants, including selection of treatments based on molecular profiling of the pancreatic cancer patient. One ongoing study was co-written by pancreatic nurse coordinator Katy Schroeder, RN, and pancreatic nurse practitioner Gayle Jameson, MSN, ACNP-BC, AOCN, who is also principal investigator of the Phase IB/II trial on the regimen of nab-paxlitaxel plus cisplatin plus gemcitabine in newly diagnosed cancer patients.

*All staff at the Virginia G. Piper Cancer Center, including the pancreatic cancer nurse coordinator, has advanced training in oncology clinical trials.*





Left: Dr. Von Hoff and Molly Downhour, MHA, BSN, OCN, confer chair side with a patient.

Below: Phase I studies at the Virginia G. Piper Cancer Center are allowing effective therapies to be brought from the laboratory directly to the patient bedside as quickly as possible.



One particularly successful trial led to the September 2013 U.S. Food and Drug Administration approval of the combination of Abraxane and gemcitabine to be used for treating advanced pancreatic cancer as the new standard of care for front-line therapy. This international clinical trial was led by Drs. Von Hoff and Ramanathan, who was principal investigator for the United States.

For Downhour, Monday mornings begin with “Genomic Rounds.” Every patient on a clinical trial is discussed at this multidisciplinary meeting of physicians, research nurses, infusion nurses, nurse practitioners, pharmacist, social worker, and financial coordinators. Separate from regular hospital tumor boards, the goal of this meeting is to make sure that each patient’s needs are met in a holistic manner. Patients on trials are seen by the research nursing staff at least twice a week to keep up with subtle (and not so subtle) physical changes that patients may experience on new drug protocols.



**Downhour’s team has written a number of cancer research grants, including selection of treatments based on molecular profiling of the pancreatic cancer patient.**

The clinical trials program uses Clincards, a debit card, to simplify management of payments to study participants. When patients on trials turn in receipts, they receive immediate reimbursement through a funds transfer to their personal card. “Some of our patients are living paycheck to paycheck, so this system offers real-time reimbursement,” explains Downhour. “Offering innovative ways to alleviate burdens for our patients is a crucial part of our care.”

On trial or off, emotional distress can be a problem for any cancer patient. The pancreatic cancer nurse coordinator uses the NCCN Distress Thermometer, coordinating with the social worker in the Virginia G. Piper Cancer Center, financial coordinators, nurse practitioners, and physicians to help alleviate patient distress.

Access to clinical trials complement the comprehensive, expert care offered at the Center for Endocrine and Pancreas Surgery at the Virginia G. Piper Cancer Center. Jeffrey A. Van Lier Ribbink, MD, FACS, leads a dedicated unit for surgical oncology.

Pancreatic surgical patients are all treated on Scottsdale Healthcare’s dedicated surgical oncology floor, contributing to better patient outcomes and development of best practices. Similar to the clinical trials team, this team of experienced nurses round with the surgeons and the multidisciplinary team to ensure patients progress without delays.

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