



Cancer Center of Excellence Award

Annual Report

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Ron DeSantis
Governor

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Cancer Center of Excellence Award Program Overview

The designation of a hospital, treatment center, or other organization as a Cancer Center of Excellence (CCE) is intended to recognize organizations that demonstrate excellence in patient-centered, coordinated care for persons undergoing cancer treatment and therapy in Florida. The goals of the CCE Award Program (section 381.925, Florida Statutes) are to encourage excellence in cancer care in Florida, attract and retain the best cancer care professionals to the state, and help Florida organizations be recognized nationally as a preferred destination for quality cancer care.

Prior to each application cycle, the Florida Department of Health (Department) contacts research and treatment facilities across the state via email to provide information about the award and the requirements.

As established in 2013, the CCE Award requires the creation of a 13-member joint committee to develop a system to distinguish cancer centers based on excellence in providing quality, comprehensive, and patient-centered care. Those components include:

- Rigorous performance measures.
- A rating system.
- A rating standard.

In addition, Florida law requires a review of these components every three years to identify if revisions are needed. Section 381.925, Florida Statutes, requires providers meet certain minimum criteria including:

- Maintain a license in good standing in this state which authorizes health care services to be provided.
- Be accredited by the Commission on Cancer of the American College of Surgeons.
- Actively participate in at least one regional cancer control collaborative that is operating pursuant to the Florida Comprehensive Cancer Control Program's cooperative agreement with the Centers for Disease Control and Prevention's National Comprehensive Cancer Control Program.
- Demonstrate excellence in and dissemination of scientifically rigorous cancer research.
- Integrate training and education of biomedical researchers and health care professionals.
- Meet enhanced cancer care coordination standards that are outlined in statute.¹

2023 Review of CCE Criteria

The CCE Joint Committee (Joint Committee) comprises six members from the Biomedical Research Advisory Council (BRAC) and seven members from the Florida Cancer Control and Research Advisory Council (CCRAB). In January 2023, the Joint Committee convened to revise the performance measures and applications for both new applicants and for the re-designation of current CCEs. The Joint Committee revised language for the following performance measure to focus on quality indicators and safety improvement.

Revised Cancer Center of Excellence Quality Indicator for Area I: Organization:

1.7 The organization demonstrates an active program of quality and safety improvement, adopts and implements a continuous comprehensive quality indicator system, reports at a minimum annually on quality metrics, and makes a summary of the evaluation available to prospective patients and family members.”

The CCE statute requires BRAC and CCRAB approval of any joint committee changes. The boards met and approved the quality indicator revision on July 17, 2023.

Calendar Year (CY) 2023 Recipient Award Update

By December 15 of each year, the Department reports the following information to the President of the Senate and the Speaker of the House of Representatives, as required by Florida Statute. The report components described in the report and answered below include:

- The number of CY 2023 applications received.
- The number of CY 2023 award recipients (new or re-designation).
- A list of award recipients.
- Recommendations to strengthen the program.

Application and Review Overview

Organizations seeking designation as a CCE submit an application and undergo a review process approved by the Joint Committee. The application and review process includes the following steps:

- Applications are submitted during one of the two application cycles offered each year.
- Department staff review applications to confirm the information is sufficient for evaluators.
- A team of five independent evaluators review written materials. Evaluators are vetted and determined to be free from conflicts of interest.
- Organizations may be asked to provide additional information and to submit revised applications.
- If a site visit is recommended during the review process, evaluators conduct a virtual site visit.
- Applicants are provided a draft application evaluation and respond with corrections and improvement plans.
- Each member of the evaluation team reviews the draft application evaluation and the organization's response, if applicable. Final recommendations for eligible organizations are sent to the State Surgeon General. The State Surgeon General notifies the Governor regarding providers that are eligible to receive designation as a CCE upon which the Governor will approve or deny the designation recommendations.

CY 2023 Applications (New and Re-Designation)

No new applications were received during the spring and fall cycles of 2023. However, in 2023 the original four CCE were required to apply for re-designation. The re-designation application process was conducted in the fall. The following institutions were up for re-designation and submitted their applications:

- H. Lee Moffitt Cancer Center and Research Institute, Inc.
- Mayo Clinic Florida
- University of Miami Sylvester Comprehensive Cancer Center

- University of Florida Health Cancer Center, which includes Shands Hospital and Proton Therapy Institute, and Orlando Health's Orlando Regional Medical Center

Additional CCEs that fall under a different re-designation schedule are:

- Memorial Cancer Institute and Florida Atlantic University
- Cleveland Clinic Florida Maroon Cancer Center

Recommendations to Strengthen the Program

Additional awareness among providers is needed regarding the CCE designation. Increasing awareness among cancer treatment centers and other facilities regarding the benefits of a CCE designation could benefit the program by:

- Increasing the number of applicants for the designation.
- Increasing the number of overall designated facilities.
- Improving the quality of treatment for cancer patients throughout the state.
- Improving health outcomes for Floridians with cancer.
- Improving the quality and quantity of cancer centers throughout the state.
- Attracting and retaining the best cancer care professionals to the state.
- Helping Florida organizations be recognized nationally as a preferred destination for quality cancer care.

To increase awareness in the coming year, the Department will contact new organizations receiving Biomedical Research Grants and provide information regarding the benefits of becoming a CCE.

Cancer Centers of Excellence Impact: Patient Stories and Their Cancer Treatment Journey

As stated throughout this report, the CCE designation is intended to recognize and identify organizations that demonstrate excellence in patient-centered care for those undergoing cancer treatment and therapy in Florida. While data and statistics can tell part of this story by outlining the numbers behind outcomes, diagnoses, and dollars spent, another side of the story can be demonstrated by the lived experiences of the patients directly affected by the care provided.

The following patient stories are self-reported by the current CCEs and highlight the real-world impact that excellent, patient-centered care can have on quality of life.

Clinical Trial Success Stories

"It meant everything just being able to try something to fight this cancer after being told by previous doctors, 'we don't know how to treat this,'" said the patient. "Just seeing the doctors that I had at Moffitt really fighting for me and, trying to find something that was a good fit and feeling like they've studied it enough to know what might work felt like they were really trying to be a fighter on my side. It was just what I needed at that moment because that's a devastating diagnosis."

The patient says he has finally gotten to the normalcy he has been striving for after participating in a CAR T clinical trial. "The puzzle pieces have come into place. I have a new lease on life. The worry of disease coming back isn't there anymore," he said. He also

offers this advice to patients who are given the option of CAR T-cell therapy: “Don’t focus on the negatives that could happen with the treatment. Stay positive and focus on how this will get you through to the next chapter of your life.”

“I was on a waiting list for [a] CAR-T [trial],” another patient said. “The goal was always to get into CAR-T, which we thought would provide a better long-term response.” Clinical trials and ongoing research continue to change what it means to be treated for cancer, and the patient hopes his story inspires other patients to stay positive and become their own advocate for treatment. “I share my story because hearing others have meant so much to me,” he said. “I had to accept that cancer has taken away a lot, and I have had to have many difficult conversations with my children. I know that my life and my story can impact other cancer patients and people of color facing a health crisis.”

“In early 2020 I was diagnosed with NUT Carcinoma a very rare and aggressive type of cancer. Everyone who has been diagnosed with NUT carcinoma has probably heard that there is no clear treatment for it. Prognosis is not very optimistic and early research doesn't give you a very nice picture either. I was very fortunate to land on an amazing team. My ENT doctor along with my oncologists and ophthalmologists work together to find not only an immediate treatment but also a cure that can go past that. It has been almost two years now that I'm on a clinical trial. It takes time, and it's not an easy process, but it can be done. I'm not in remission but I'm stable. two years, eight months, and counting...believe me, that every MRI that shows that I am stable, and stable is a good word, is proof that there is hope for me and for everyone.

“I was excited about the opportunity to participate in a trial. I actually gave up free treatment at the Veteran’s Administration to participate. I have a great relationship with the research coordinators, making me feel at ease and comfortable to ask questions about my care. They are more available than the doctors or physician assistants and I appreciate the time spent with me. They have helped me maintain a positive outlook through my treatment.”

Patients Giving Back

“It’s hard to grasp how cancer will affect the rest of your life,” said a young breast cancer survivor. “The institution’s AYA [adults and young adults] Program takes away a lot of the unknowns. It provides a way to connect with survivors who have gone through similar experiences and have a safe space to talk with supporters during very confusing and uncertain times.” The patient says she became an ambassador to give a voice to a population that often feels unseen, so they know there are people fighting for their best possible outcomes. One of her goals as an ambassador is to ensure all the institution’s patients ages 15 to 39 know about the AYA Program. The AYA ambassador committee meets once a month to discuss patient needs, provide insight on initiatives and brainstorm new ways for the institution to provide the best experience for younger patients. Because of her personal cancer journey, the patient chose to pursue a career at the institution. She began working at the cancer center in March 2022, where she is thriving in her role as a research coordinator.

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Since his diagnosis with pancreatic cancer, another patient has also been a big advocate to help raise funds for cancer research. “Without the research, care and courage the institution provides, I wouldn’t be a survivor today. One of the most shocking things you can hear is that ‘C’ word. It scares you to death,” he said.

“Everybody is fighting for a cure, and everybody affected by this horrible disease needs support. I’m so blessed by the medical team and want to do everything I can to raise awareness for pancreatic cancer.”

Treatment Success Stories

“I had a kidney transplant at 15 and seven years later, in 2011, I found out that the transplant had failed,” a young patient said. “At that same time, I found a lump on my breast and told a nurse. She and the doctor sent me for an ultrasound and a mammogram, and it came back as abnormal.” Two days after tests, she learned that at age 22 she had stage four breast cancer. Just weeks after returning to dialysis to keep her kidneys functioning, referral was made to the institution, and she met with the medical oncologist. She learned that she had to beat the cancer before she could be eligible for another kidney transplant. After the patient was declared cancer-free, she went back to college. “At that time, I didn’t qualify for a new kidney because you have to wait five years after cancer treatment to make sure you remain cancer free,” she said. “But I was able to go back to college.”

“My dream is to work alongside the institution’s team and to be able to touch the lives of cancer patients the way the nurses there touched my life,” she said. “After going through cancer myself and experiencing the treatment at the institution, I think I found where I want to be. I want to be an oncology nurse where I was treated.”

“When it came time for treatment after being diagnosed with stage 1b lung cancer, the band director-turned patient didn’t stop at a second opinion — he got four. His final consultation was at the institution where he immediately made the decision to begin treatment after speaking with the medical oncologist. It was an easy choice because this is what the institution does,” he said. “It has the reputation and the research, plus the

geography.” Six weeks after his surgery, he started his first of four cycles of chemotherapy. The treatment was a success. This November will mark his 16th anniversary of being cancer free. He continues to receive annual scans and checkups at the institution.

As a recreational athlete, the patient wasn’t initially alarmed when he first noticed some swelling in his right testicle. The young father plays basketball two to three days a week and participates in a men’s ice hockey league every season. The patient decided it was time to see a doctor after the swelling in one of his testicles kept getting worse. Initial imaging revealed that the swelling in his right testicle was actually a tumor. The patient’s urologist recommended immediate surgery. Before deciding how to proceed, they received a call from a senior member in the Department of Genitourinary Oncology. “We never had any experience with cancer or having to make a rush decision to have surgery,” the patient’s wife said. “I just remember being amazed that a doctor would take the time to call us personally when we weren’t even a patient yet. He assured us this was the right course of action.” Today, the patient is cancer free. He and his wife want to use their cancer journey to urge other families to be aware of their own potential health issues.

“I was diagnosed with Hepatosplenic T-cell Lymphoma. I went through multiple rounds of chemotherapy and then had a bone marrow transplant. After my transplant I had many complications including Chronic GVHD (graft versus host disease). So, I came to the institution to seek the best treatment options for my Chronic GVHD. When I arrived, I met with the physician, and he suggested I start Extra Corporeal Photopheresis (ECP). I have now been doing ECP here for over a year. This institution has changed my life by making my treatment fun. My hope for the future is to be cured of my disease and to go on and help others. Cancer care and research will change the future by allowing patients to receive the best and least harmful treatment options.”

“It is quite possible that my healthcare team did more than change my life, they may have saved my life. I was diagnosed with a rare sarcoma 700 miles from Miami but thankfully found my way to the institution after realizing that my local doctors did not adequately understand the disease. This institution means the opportunity to live, and I have great hope for the future with my cancer because I know that this team ‘has my back’. Research is vital and even more so when dealing with a rare cancer. My cancer community needs more treatment options and I appreciate and support the research conducted at the institution specifically for gastrointestinal stromal tumor.”

“As a three-time Cancer survivor of Stage-4 Hodgkin’s lymphoma and Stem Cell transplant recipient in 2016, I have been truly blessed to have had the opportunity to be treated right here in my hometown at the institution’s Comprehensive Cancer Center. I’ve been through it all! Blood tests, cat scans, pet scans, biopsies (spine, chest, and bone marrow), transfusions, radiation, chemo, stem cell transplant and through it all, the healthcare team was there for me and my family. Because of my wonderful experience, I have had the honor to help other survivors and their caregivers through our Patient and Family Advisory Council and many other volunteer and support opportunities.”

“I never truly realized how life can completely change overnight. When I moved five years ago, I was very excited to start a life here in Miami, but this new life turned out to be a significant challenge. In 2017, at 14 years old, I was diagnosed with Acute Myeloid Leukemia in a very advanced stage. I had to start treatment right away and before I knew it, I was in a hospital bed having no idea of what would happen next. After a few rounds of chemotherapy treatment, in May 2018, thanks to the incredible generosity of an unrelated donor, I had a Bone Marrow Transplant. As you can imagine, all this process signified a drastic change in my everyday life. It entailed having to spend months in a hospital bed, barely being able to walk, and going through countless surgeries. But, despite everything, I always had the support of my family, friends, doctors, and nurses, and I know I couldn't have done it without them. This life experience has changed my perspective towards life and taught me that the future is uncertain, and the present is a true gift.”

“I conquered breast cancer because the institution offered me comprehensive care lead by my Oncologist along with their outstanding team. I'm truly living my best life as a survivor because of their knowledge, skill, research, care, and kindness. I chose the institution because I trust it. I worked there for over 30 years, and it is like my second home. The experience is unbelievable. So many years of research and patient care make a difference. Everything changed when I went there for treatment. My health changed. I was a stage 4 pancreatic cancer patient, and now I am cancer-free.”

“My journey started in 2017 when I went to my gynecologist for my annual exam and was told my pap smear showed cancer cells. I contacted the institution's Comprehensive Cancer Center Division of Gynecologic Oncology and was given an appointment. The provider ordered more tests and determined that yes, I had cervical cancer. I thought it was very surreal, from working for the division of gynecologic oncology to then becoming a patient. Throughout this experience, the healthcare team were the best. My treatment ended in March 2018, and as of now, I am still in remission. I feel the same way I felt before the diagnosis. I feel my ambition has returned and my drive to get into real estate and enjoy my hobbies of fishing, flying drones, and repairing and programming computers. All my life's pleasures have come back now and have returned times three, and this time with Supreme Purpose! I am so sincerely grateful for my Supreme Dream Team.”

Compassionate Care

The doctors and nurses in the Clinical Research Unit care deeply about their patients as evidenced in the select quotes highlighted below:

“When a patient compared the Cancer Center to Disney World, her daughter didn’t quite understand. ‘I thought what an odd comparison,’ she said. ‘But I get it now. She thought of the institution as this magical place. This place where you go in, there’s hope and miracles happen.’ The patient was looking for a miracle when she was diagnosed with advanced lung cancer in 2019. She had just turned 69, celebrated her 50th wedding anniversary and had no symptoms. Doctors told her there was nothing that could be done and to get her affairs in order. One of the patient’s daughters says she is grateful the institution made it easy for her to be involved in her mom’s care. ‘Having her care coordinated where you had one place where all the doctors were talking and sharing information made me feel like she was getting the best treatment. But it was more than just that. It was more of the people that we got to know along the way,’ the daughter said. ‘While my mom’s story didn’t end the way we wanted it to end, I know for a fact that the people there at the institution gave her more time,’ she said. ‘We got more time and more birthdays, more holidays, more time to make memories. And for this, and I know my mom would want to make sure everyone there knew just how grateful she was for that’.”

“The staff don’t make you feel like a patient they treat you like they would want their family member treated! Outstanding staff!!!”

“My nurse was exactly who I needed on my first day of chemotherapy and the clinical trial. She took her time, she explained everything, and she was so sweet.”

“My nurse in the Clinical Research Unit has been exceptional in her teaching, care, and kindness. She is always professional and patient. She is an absolute asset to the Clinical Research Unit at your facility!!”

“I never thought that I was considered just a ‘number.’ Everyone treated me with respect. I believe I couldn’t be in a better place for my care!”

“I’ve never have had such a caring and professional team driven group of knowledgeable personnel take care of me! I’ve been so blessed and grateful for each and every one of them!”

“The institution means a lot to me because of the doctors on my team and their curative care. I received an expected skin reaction from my Radiation Therapy that resolved with appropriate management, but the physicians made me feel comfortable going through the 30 sessions of therapy.”

“Throughout my experience being treated with breast cancer, I realized there was consistency in care. I received treatment at several of the institution’s facilities. At each location, the staff and medical team were always welcoming. I did most treatments at mainly one location, and everyone knew my name. They asked about my daughter, who went away to college shortly after I began chemotherapy. With all the patients they had, it warmed my heart for them to know me! I feel the institution provides an array of treatment options and services from diagnosis to survivorship. There are various clinical trials available especially when traditional procedures are not an option.”

“In May 2018, I was diagnosed with advanced Follicular Lymphoma—the cancer had spread throughout my body except the brain. It was the beginning of a three-year battle with cancer and after a bone marrow transplant, I reached remission. The oncologists went above and beyond to make my experience comfortable during my struggles with extensive chemotherapy and awful side-effects. They became part of my family, the care and attention to detail, earned them my complete trust. The support team, consisting of other specialists like Psychiatrist, Nutritionist, Physical therapist, Psychologist, among others, as well as the nurses, created the right caring environment for me to find the strength to beat the disease. Even at my lowest point when I was about to lose my house, the institution came to the rescue. The center assigned a social worker to work with the county’s Legal Aid to find a lawyer willing to represent me for free to address my legal issues while I continued my treatment. The attorney made sure I did not lose my house, giving me back the strength to focus on the treatment. If I did not have this additional support, the stress of losing my house during the treatment would have killed me. The healthcare team put together to care for me, provided a holistic approach to ensure that I had the wherewithal to survive not only death but the most banal misfortunes that afflict cancer survivors: economic struggles from not working during and post treatment. I’ve never encountered another hospital like the Comprehensive Cancer Center—they truly care deeply about repairing the lives of cancer patients.”

“My oncologist found me when I needed him the most. I received my cancer diagnosis in the early morning hours in the emergency department after going in for back pain. I was scared and overwhelmed and didn’t know where to turn. The compassionate, knowledgeable care and support I received from our first meeting gave me hope and saved my life. Overall, I couldn’t imagine going through treatment anywhere but this institution. I also received amazing support and guidance from my oncologist's partner. The theme of compassionate care was carried out by many of the nurses who brought joy during a dark time. The multiple locations were close to my house, so I never had to worry about scheduling treatments even on the weekend. And the additional services like nutrition, physical therapy, and massage therapy all supported me in my recovery. I’m nine months out of treatment and thriving! I’m back doing the things that I love; I took up rock climbing after treatment and just completed my first 45’ ascent!”

“The healthcare professionals at the Comprehensive Cancer Center are caring, compassionate, knowledgeable, kind and patient. Those characteristics help so much during my eight-year-old son’s cancer treatment. The child-life specialists really went out of their way to make each appointment comfortable for him. They brought gifts and activities for him to use while he got his chemotherapy. It helped him take his mind off the

uncomfortableness. We are so grateful to everyone for the amazing level of care and compassion.”

“My research coordinator is always easy to get on the phone for questions. She calls us to keep us updated, too. She was really helpful when it came to getting my medication and also got me in touch with the social worker for help with another really expensive medicine that they wanted me to take. We really appreciated that because we couldn’t have afforded it otherwise.”

“My research coordinator is awesome! She always keeps me updated and I always know what to expect. When we talked about the study the very first day it was really relaxed and not confusing. She and the doctor answered all my questions.”

ⁱ As referenced in statute, enhanced cancer care coordination standards include: coordination of care by cancer specialists and nursing and allied health professionals, psychosocial assessment and services, suitable and timely referrals and follow-up, providing accurate and complete information on treatment options, including clinical trials, which consider each person’s needs, preferences, and resources, whether provided by that center or available through other health care providers, participation in a comprehensive network of cancer specialists of multiple disciplines, which enables the patient to consult with a variety of experts to examine treatment alternatives, family services and support, and aftercare and survivor services.