I May Dance with the Devil, but I Am Going to Lead

Nellie Singh never imagined she’d be back to living with her parents when she was in her mid-40s, but that’s where she finds herself as she battles stage 4 lung cancer. The once social, energetic, multi-tasker, who ran six restaurants in Manhattan, says she is basically off the grid.

Doctors diagnosed her with non-small cell adenocarcinoma after she found a small swollen area on her neck that she thought may have been an allergic reaction to perfume. The swelling quickly grew from the size of a dime to the size of a quarter. It was actually the result of a tumor that spread from her lungs to her sternum to her lymph nodes, making surgery impossible. Singh is quick to point out that coughing isn’t always a symptom of lung cancer, which means patients like her are not diagnosed until the cancer spreads.

Singh was shocked because she was in her early 40’s, didn’t smoke and never had any health issues, not even a cavity. Plus, she didn’t have any symptoms until she noticed the lump on her neck while putting on a turtleneck. Her first thought was, “I lost a friend who had stage 4 cancer and now I have stage 4 cancer. I felt like I was already dead.”

Singh began intravenous chemotherapy treatment on her 43rd birthday. Though she underwent radiation therapy simultaneously, she says she was in denial about the disease for the first year. Like many people, she assumed lung cancer was reserved for older men who smoked. Singh says she is often asked if she is lost when she walks into support groups because she doesn’t fit the typical lung cancer profile.

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UPCOMING EVENTS

January – February – March

Arts In Medicine Studio, 813-745-8407
Open Arts Studio: relax, create, express, discover and share inspiration
MCC – Every Mon. - Fri., 9:30 a.m.–4 p.m.,
Arts Studio, 3rd floor, elevator B
MKC – Every Mon. – Fri., 8:30 a.m.–5 p.m.,
Patient and Family Center, 1st floor, by Publix Pharmacy

AYA Lounge Night, 813-745-4736
MCC – Every second and fourth Thur.,
5–7 p.m., AYA Lounge, 4th floor, use elevator C

Gentle Restorative Yoga, 813-745-6052
MRC – Every Tues., 12-1 p.m., Yoga Room

Meditation/Relaxation Classes, 813-745-6052
MCC – Every Wed., 12:15-1 p.m., Day Room,
5th floor, use elevator C

Meet the Expert Series, 813-745-4710
Cancer experts share information on various topics
MCC – Every Mon. - Fri., 10-10:30 a.m.,
Patient Library & Welcome Center, 2nd floor, elevator B
MKC – Thursdays, 10:30-11 a.m., Patient and Family Center, 1st floor, by Publix Pharmacy

New Patient Chemotherapy Class
Magen.Davis@Moffitt.org
MCC - Owl's Den - Every Mon., 12-1 p.m.,
1st floor
MCC - Owl's Den - Every Thurs., 1-2 p.m.,
1st floor

JANUARY

Thur., January 2 and 16 – Acupuncture for Stress Relief in Group Setting, 9–10:20 a.m., MRC Yoga Room, free (accepts donations up to $5.00), reservations required, 760-710-7836

Wed., January 8 – Tools to Quit, free quit smoking class and free nicotine patches, 2–4 p.m., MCC,
Owl’s Den Meeting Room, 1st floor, 813-745-8811 or TobaccoTreatment@Moffitt.org

Thur., January 9, 16, 23, 30 – Coffee Connection, 9:30–11:30 a.m., MCC, Owl’s Den Meeting Room, 1st floor

Wed., January 15 – Music & Art à La Carte, event featuring a Musician-In-Residence paired with one of our Artists-In-Residence, 1–2 p.m., MCC, Cafeteria Entrance, Basement, 813-745-1836 or Amanda.Bonanno@Moffitt.org

FEBRUARY

Sat., February 1 – Bridging the Gap in Neurofibromatosis, conference involving patients, families and health care providers sharing new advances in the field of neurofibromatosis, 10 a.m.–3 p.m., SRB, David Murphey Conference Room, reservations required, NFConference@Moffitt.org

Thur., February 6 and 20 – Acupuncture for Stress Relief in Group Setting, 9–10:20 a.m., MRC Yoga Room, free (accepts donations up to $5.00), reservations required, 760-710-7836

Thur., February 13, 20, 27 – Coffee Connection, 9:30-11:30 a.m., MCC, Owl’s Den Meeting Room, 1st floor

Wed., February 19 – Music & Art à La Carte, event featuring a Musician-In-Residence paired with one of our Artists-In-Residence, 1–2 p.m., Moffitt McKinley, Main Lobby, 1st floor

MARCH

Thur., March 5, 19 – Acupuncture for Stress Relief in Group Setting, 9–10:20 a.m., MRC Supportive Care Medicine Clinic, Free (accepts donations up to $5.00), 760-710-7836

Tue., March 10 – Survivors Overcoming and Achieving Resilience (SOAR), 8-weeks interactive workshop for breast cancer survivors, 5:30–7:30 p.m., MKC, Gruden Huddle Room, 1st floor, (across the Patient and Family Center) RSVP required, 813-745-6573 or Dianne.Riccardi@moffitt.org

Tue., March 10, 24 – Caregivers’ Coffee Connection, 9:00–10:30 a.m., MKC, Gruden Huddle Room, 1st floor, (across the Patient and Family Center)

Wed., March 11 – Tools To Quit, free quit smoking class and free nicotine patches, 2-4 p.m., Muriel Rothman Building, Owl’s Den Meeting Room, 1st floor, 813-745-8811 or TobaccoTreatment@Moffitt.org

Thur., March 12, 19, 26 – Coffee Connection, 9:30–11:30 a.m., MCC, Owl’s Den Meeting Room, 1st floor, (around the corner from Blood Draw)

Wed., March 18 – Music & Art à La Carte, event featuring a Musician-In-Residence paired with one of our Artists-In-Residence, 1–2 p.m., MCC, Radiation Therapy, 1st floor

Visit Moffitt.org/Calendar for more upcoming events!
When Singh introduces herself she's quick to say she has stage 4 lung cancer, but is a non-smoker. She says it so fast it sounds like it's all one word because she feels there is a stigma associated with lung cancer that a person must have brought it on themselves by smoking. In fact, she would get very angry at anyone she saw smoking and even shouted at a healthcare worker who implied the cancer was her own fault.

According to the American Cancer Society, 20% of people who die from lung cancer never smoked or used any form of tobacco. Singh says she has a rare mutation in a BRAF gene, but she doesn't dwell on how or why she got cancer. Instead, she has her sights set on helping others with cancer and trying to eliminate the stigma associated with lung cancer. She joined numerous support groups and volunteers with Speak Out for Moffitt, Imerman Angels and is a peer-visitor with Moffitt's Patient and Family Advisory Program's Coffee Connections.

Singh says doctors told her that while she has no evidence of disease at the moment she will never be cured because tumors will continue to pop up throughout her life. They advised her to receive intravenous chemotherapy once a month, along with quarterly scans. If another tumor develops, they may change the chemotherapy, move on to targeted therapy and then transition to immunotherapy treatments. This plan didn't sit well with Singh who experienced cognitive impairment, nightmares and other psychological issues from the chemotherapy. She also says she suffers from severe anxiety before and after her three-month scans. “How do you call yourself cancer-free if you have to keep coming in to see if the devil is still there,” Singh said.

Ultimately, Singh decided to take a “chemo-break.” She is no longer receiving chemotherapy treatment and chooses to have her scans every four months instead of every three months to improve her quality of life. She plans on continuing down this path until her body tells her otherwise. She says she feels like she is starting all over again as she looks forward to a new chapter in her life that focuses on volunteering and advocating for lung cancer patients.

If you would like to learn more about becoming a peer visitor with Moffitt’s Patient and Family Advisory Program, please email PatientAdvisors@Moffitt.org or call 813-745-2963.

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**Imerman Angels: “One-On-One” Support**

Moffitt partners with Imerman Angels to further meet the needs of our patients and their loved ones. Support is provided to both patients and family members by partnering them with a Mentor Angel, a trained volunteer who has been through a similar cancer experience based on cancer type, stage and lifestyle.

ImermanAngels.org
1-866-IMERMAN (463-7626)

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**Speak Out for Moffitt**

A coalition of patients, families, health care professionals and community members united in support of Moffitt’s efforts to fight cancer. These volunteers advance state and federal policy issues by sharing stories about how Moffitt has impacted their lives or the lives of people they know.

SpeakOutForMoffitt.org
813-745-1221
GovernmentRelations@Moffitt.org
MESSAGE FROM THE CO-CHAIR

Shani Parkin, Co-Chair
Patient and Family Advisory Council

Volunteering Is a Work of Heart

It’s hard to believe that I have almost completed my first year as co-chair of the Patient and Family Advisory Council (PFAC). I could not have achieved this without the support of our extremely dedicated and talented council members and my partner co-chair, Debbie Phillips. Since the beginning of my first volunteer role as a patient advisor in 2015, Debbie has mentored and guided me through various steering committees and other supportive role assignments, including recommending me as a candidate for PFAC in 2017. After more than eight years of service, Debbie’s tenure as co-chair is now completed. On behalf of our patients, caregivers, volunteers and the PFAC team, I would like to thank Debbie for her dedicated service and outstanding leadership; she will be sadly missed.

PFAC serves as a “voice” for patients and caregivers who have received cancer treatment at Moffitt and their families. Members serve as a resource on a wide variety of issues, services and policies and work alongside doctors, nurses, other health care providers and administrators to provide information on behalf of our patients and caregivers about their needs and concerns.

I am delighted to introduce you to our new co-chair, Patti Halula. Patti is both a Moffitt patient and volunteer with a tremendous “can-do” attitude and is a truly amazing advocate for both our patients and their families.

With Patti as my co-chair, you can be assured that she and the PFAC team will continue to be your voice at Moffitt.

For more information about the Patient and Family Advisory Council, please email PatientAdvisors@Moffitt.org or call 813-745-2963.

The Chemo Class

Caroline Stallings, BSN, RN, Infusion Center Assistant Patient Care Manager

Are you interested in learning more about chemotherapy? The Infusion Center nursing and pharmacy teams have come together to provide an educational class for patients, families and caregivers. The class includes information about chemotherapy, how it is given and what to expect during treatment.

You also will learn about potential side effects and how to handle them, along with what concerns you should call your doctor about.

We understand that receiving a cancer diagnosis and getting chemotherapy can be overwhelming – and you may have many questions. That is why our team wanted to offer this course, focused solely on chemotherapy, to help answer your questions and alleviate any concerns you may have.

The Chemo Class is offered every Monday 12-1 p.m. and every Thursday 1-2 p.m. at the Owl’s Den on the 1st floor of the Magnolia Campus. During this one-hour class, you will have the chance to ask questions and talk with an experienced chemotherapy nurse and pharmacist. For additional information, please send an email to Dawn.Stallings@Moffitt.org or call 813-745-7832.

Please stop by and join us for one of our classes. We hope to see you there.
Patient and Family Support Groups

The following support groups are offered at Moffitt Cancer Center.

To learn more about any of the support groups offered, including times and locations, please call the Social Work Office at 813-745-8407.

Cancer Support Group
Support group for patients with any cancer diagnosis. Meets every Tuesday, 1-2 p.m., USF Magnolia campus, 5th floor lounge of the hospital. Use elevator C.

Family and Friends Support Group
Support group for family members, friends and caregivers of cancer patients. Meets every Tuesday, 1-2 p.m., USF Magnolia campus, 5th floor of the hospital, room 5140 A. Use elevator C.

Metastatic Breast Cancer Support Group
Support group for patients with Stage 4 metastatic breast cancer. Meets weekly for six-week sessions throughout the year at the Administrative Conference Room, 2nd floor, McKinley campus. Please call 813-745-7269 for dates and times.

Breast Cancer Support Group
Support group for all patients with breast cancer meets the first Tuesday of every month, 6:00-7:00 p.m. at the Administrative Conference Room, 2nd floor, McKinley campus. All breast cancer patients are welcome regardless of stage of treatment.

Lung Cancer Phone Support Group
Monthly phone support group for patients with advanced lung cancer. Meets the first Wednesday of the month from 2-3 p.m. Please call social work office for all call-in instructions.

Families First
A special, bi-monthly free program for parents with cancer and their young children (ages 5-18). For more information, please call 813-745-1811.

Cutaneous T-Cell Lymphoma (CTCL) Support Group
A monthly support group for patients with CTCL. Meets the third Thursday of every month, 4:30-5:30 p.m. in the Cutaneous Clinic, McKinley campus.

Finding Balance with Cancer
A 4-week stress reduction program jointly offered by the Integrative Medicine Program and Social Work. Patients and caregivers learn mindful meditation techniques through group discussion and guided practice. Please call 813-745-2014 for next 4 week session.

Caregivers of Patients with Brain Tumors/Brain Metastases Phone Group
Monthly phone support group for caregivers of patients with brain tumors or metastatic disease to the brain. Meets the second Friday of the month from 2-3 p.m. Please call social work office for all call-in instructions.
In September 2018, Moffitt was awarded a $500,000 grant from the National Cancer Institute to help improve our patient’s access to tobacco cessation services. This grant opportunity was part of the Cancer Moonshot initiative announced in 2016 to help accelerate advancements in the treatment and prevention of cancer. This prestigious grant reflects Moffitt’s dedication to healthy lifestyles and providing holistic patient- and family-centered care.

Using tobacco during and after cancer treatment can reduce the effectiveness of a patient’s cancer treatment and increases the risk of developing a secondary cancer or cancer recurrence. Moffitt currently has one Tobacco Treatment Specialist (TTS) that sees patients based on referral by a nurse, doctor or social worker. As a result, not all patients who use tobacco get information, resources or counseling to help them quit.

We understand that quitting smoking can be very difficult so we are very excited that through the support of this grant, at Moffitt we will now be able to offer every patient who uses tobacco help from the moment of their first appointment. Moffitt has partnered with The Florida Bureau of Tobacco Control to develop a seamless electronic referral process to connect patients with their toll-free tobacco quitline to obtain help with quitting. We will also be hiring an additional Tobacco Treatment Specialist to help ensure all patients who request face-to-face counseling have access to this service. Lisa Sloan, MPH, tobacco treatment specialist states, “I am excited about everything we are doing to expand our tobacco program. We will now be able to offer every patient the support they need to quit smoking and improve their cancer treatment outcomes.”

It’s never too late to quit smoking. Even if you have tried before and not succeeded, every effort helps in getting you closer to being smoking free. If you or a family member is interested in quitting smoking please call our Tobacco Treatment Specialist at 813-745-8811 or Tobacco Free Florida at 877-822-6669.
Have you ever wanted to manage upcoming Moffitt appointments or message your providers from anywhere at any time? Now there’s an app for doing just that. Moffitt’s patient portal is now available as an app for iPhone and Android devices.

Simply search for “MyMoffitt” in the app store and install it on your phone. Please note that you must first sign up for a MyMoffitt Patient Portal account by visiting https://mymoffitt.iqhealth.com/self-enroll. Once you have an account, simply sign into the app with your username and password.

The MyMoffitt Patient Portal app has all of the same functions as the desktop patient portal, except everything is right at your fingertips via smartphone or tablet.

Through the MyMoffitt Patient Portal app you can:

- View upcoming appointments and appointment instructions; request new appointments or changes to existing appointments.
- Complete the patient questionnaire, prior to appointment.
- Securely communicate with Moffitt providers to request prescription renewals and send non-urgent health-related messages.
- View and request updates to personal health information.
- Review approved lab results 36 hours after being completed by the lab.
- View your complete medical record with few exceptions. Notes and documents are available immediately after a physician signs off.
- View radiology and pathology notes. These notes have a delay associated with them prior to being viewable in your portal account.
- View and pay your hospital bill statement(s), schedule payments or make a one-time payment.
- Find other helpful educational information.

If you have questions, call the Patient Portal support line at 813-745-8111.

Caregivers’ Coffee Connection

Every 2nd and 4th Tuesday of the Month
9:00–10:30 a.m.

Moffitt’s McKinley Campus
1st Floor
Gruden Huddle Room
When I was a patient and received an email or text asking me to complete a confidential survey about my recent visit to Moffitt Cancer Center, the following thoughts often ran through my mind:

- Do I even want to respond to this?
- Is it truly confidential?
- Does my opinion actually matter?
- Will being honest with my thoughts result in lesser quality of care?
- This seems like a waste of time; does it really accomplish anything?

However, due to my recent volunteer involvement on Moffitt committees where these Press Ganey surveys are discussed, I now realize what an important role they play in helping Moffitt to continue to grow and truly embrace the patient experience.

If you receive one of these surveys, let me assure you that your responses are completely confidential.

These survey results provide key information that enables Moffitt to focus on areas that need improvement, as well as praise exemplary team members. All Moffitt personnel benefit from your insight, from the receptionist who greeted you upon arrival to the medical assistant who took your blood pressure to the physician who met with you.

Think about the precious time you, as a patient or caregiver, spend with the Moffitt professionals. Every moment of your visit is vitally important to both you and your Moffitt team.

Your feedback may help your future visits (and those of other patients) be more streamlined and efficient and may also facilitate better communication between patients and providers.

Moffitt wants to hear from you. Please share your thoughts by completing your surveys.

Laura Barber, Patient Advisor, Patient and Family Advisory Council

YOUR VOICE MATTERS

Learn How Sharing Your Voice Can Impact the Patient Experience

Ask about the Patient and Family Advisory Council at PatientAdvisors@Moffitt.org.
Often, when patients attempted to contact a clinician with questions and concerns, the process varied from clinic to clinic, sometimes resulting in numerous voice messages or emails. Our patients and their loved ones waited in anticipation for the phone to ring, hoping it was someone with a response. It was frustrating and disheartening, and we saw the problem reflected in our patient satisfaction scores and team member dissatisfaction with the process. Unfortunately, this experience was the reality for many patients at Moffitt.

In 2017, after analyzing the feedback we received in the patient satisfaction survey and other sources, the cancer center began planning the Communication with Established Patients (CEP) initiative with the ultimate goal of creating a better patient experience. This initiative took on the task of standardizing clinic procedures and creating a better link between patients. Now patients can call one centralized phone number (813-745-8000) and reach a live representative who helps the patient, creates a message to the clinical team or transfers the patient to a clinical team member who can better assist. They have found that about half of the calls do not need a nurse or provider, which increases response time to the patient and allows the clinical team to focus on those most in need. From the onset, the project had patient advisors on the team to ensure that the voice of the patient was considered throughout. The CEP initiative has been rolled out clinic-by-clinic and all clinics live with CEP by late Fall 2019.

The results so far have been very positive. The percent of patients who have their issues resolved within 24 hours has reached 96%, the patient satisfaction scores related to reaching their medical team have improved an average of almost 2%, and now patients can easily reach a live person when they call. The success of this initiative shows what is possible when we listen to what matters to our patients, include them in improvement processes, and truly partner with them for an exceptional experience.

### SPOTLIGHT ON

How Patient Satisfaction Surveys Lead to Improvements

*Terry Payton, Manager, Patient Experience/Satisfaction*

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### CALL PATIENT CARE HOTLINE

**813-745-8000**

Mon.-Fri. 7 a.m.-7 p.m.
Sat. 8 a.m.-12 p.m.

Speak to a communication specialist who immediately assists with:

- Questions
- Clinical Concerns
- Scheduling Needs
And more…
To say David and Vesta Alexander do everything together is an understatement. The husband and wife team battled cancer twice side by side, recovered from bone marrow transplants at the same time and were discharged from Moffitt Cancer Center on the same day.

In 2015, David began feeling exhausted and out of breath. He instinctively knew something was wrong, but couldn’t quite put his finger on it. Doctors diagnosed him with anemia after discovering he had a low red blood cell count. But, things didn’t get better and it took the next 18 months to figure out what was wrong.

Eventually, David ended up at Moffitt where doctors diagnosed him with chronic myelomonocytic leukemia (CMML) and recommended a bone marrow transplant. Fortunately, the team found three matching bone marrow donors in a short period of time. Without a donor, he would not have survived. David underwent eight months of chemotherapy including 26 days of intensive, inpatient chemotherapy before having the bone marrow transplant. “The transplant was uneventful. It was like a blood transfusion,” David explains. “Chemotherapy was much worse, but the recovery was rough because I had to build up strength.”

While David was undergoing treatment, Vesta set about caring for her husband and preparing for his transplant and recovery. She is a retired school teacher who prides herself on being organized. She was so focused and busy that she ignored changes in her own health.

Eventually, she went to the doctor and was diagnosed with multiple myeloma, a form of leukemia, the week David entered the hospital for his first round of intensive chemotherapy. In fact, her physician said her blood count was as low as David’s. The only difference was that he was in the hospital and she was out and about. David felt more determined than ever to get better because he had to care for his wife.

As surprising as the diagnosis was, it was not the Alexanders first time facing cancer together. In 2001, doctors diagnosed Vesta with breast cancer and a year later David discovered he had colon cancer.

Like David, Vesta needed a bone marrow transplant. But, unlike her husband, she was able to use her own stem cells. David had his bone marrow transplant five weeks before Vesta’s was scheduled. She watched his recovery carefully, knowing she’d be going through the same thing.

David lost his hair and couldn’t brush his teeth or shave. He avoided mirrors during this time and Vesta vividly remembers walking into his hospital room and seeing David with half a mustache. The other half had fallen off, but he couldn’t shave the half that was still there.

Like her husband, Vesta also lost her hair during treatment. Her granddaughter, who battled leukemia six years ago at the age of three, was by her side picking out hats like ones she used to wear. Both David and Vesta were discharged from the hospital on the same day. Family and friends helped a lot during their recovery. They also relied heavily on each other because they truly understood what each other was going through. They both meticulously followed their physician’s instructions even if it meant not doing some of the things they loved to do. One of the hardest things for David, an avid gardener, was not being allowed to go in the sun or touch plants.

Today the Alexanders are doing well. David still has to be careful in the sun, but he can garden, paint and remodel their home. They say they learned a lot and appreciate every day. They also celebrate their new birthdays each May by taking a month-long trip. So far they’ve been to Greece and Italy and wherever their travels take them they know they will do it side by side.
My husband, Ralph, and I were together almost 35 amazing, incredible years. We loved each other and enjoyed our life together. We knew if we loved Jesus best, we would love each other deeper every day. We retired on the same day, January 27, 2012, and the good times got even better. However, nine months after we retired, our world was rocked when Ralph was diagnosed with inoperable pancreatic cancer. Moffitt, the top-ranked cancer center in the southeast, is right in our backyard. Moffitt gave us hope! God placed Ralph in Dr. Richard Kim’s care and, together, we pursued this horrible disease with the latest protocols. Ralph fought pancreatic cancer for almost four years with 75 rounds of treatment and five different strains of chemotherapy. Jesus, our Bay Hope Church family, Moffitt, Dr. Kim, and so many miracles along the way allowed us to keep writing our love story.

We never gave up hope that the next new treatment to end devastating cancer could be right around the corner. We prayed relentlessly that God would lead the Moffitt doctors, nurses, administrative staff, and researchers to a cure now!

Moffitt gave Ralph and me four more years together that we wouldn’t have had if he’d been treated anywhere else. On September 27, 2016, Ralph met Jesus face-to-face. It was his brightest light and my darkest moment. Life without Ralph is like a painful amputation – part of me is gone. But because Moffitt gave us so much, I know Ralph would want me to give back in this new season of my life.

In July 2018, I joined the Patient Family Advisory Group. I understand the patients’ and caregivers’ journeys. My faith inspires and strengthens my desire to be a light of hope in the dark world of cancer. The committees I am a part of allow me to share our experiences, giving the professional staff a caregiver’s perspective for what Moffitt does well and what it could do better.

I am grateful for Moffitt and pray each day for the doctors, researchers, and staff…that their tireless efforts and dedication will one day lead to wiping out this ugly disease.

Cathy with her husband Ralph

Moffitt employs clinically trained board-certified chaplains. The chaplains do not represent any one faith group. They meet each person where they are and help them tap into spiritual resources they may already have or help them discover spiritual resources to assist them in their cancer journey. Chaplains may be reached by calling 813-745-2856 or by calling the hospital operator 813-745-4673 and asking to be connected to a chaplain. The Interfaith Chapel at the Magnolia campus is open to all 24 hours a day.
Patient and Family Orientation

Learn how to:
CONNECT WITH PROGRAMS AND SERVICES
PARTNER WITH YOUR CARE TEAM
FIND YOUR WAY AROUND MOFFITT

• 30-minute orientation
• Presented in English and Spanish
• Scheduled Monday- Friday,
  Call us! We’ll find a time that works for you.
• Walking tours on select days
• View online at Moffitt.org/Orientation
• Receive a free messenger bag with Moffitt resources and organizational tools.

813-745-4710 | Orientation@Moffitt.org.