

Precision

May 2014



A newsletter from the University of Florida Proton Therapy Institute • www.floridaproton.org • Phone: (877) 686-6009

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It is easy to stay in touch with us online at www.floridaproton.org. Look at the top right corner of the homepage for Facebook, Twitter and YouTube icons, click and join us in the social media conversation. Also on the right side of the homepage there is a button for [VTOC Patient Portal](#). Click here to open your secure account, view your records, complete clinical trial questionnaires and communicate with your nurse case manager. Knowing how you are feeling during and after treatment is essential to providing you the best care possible and contributes to the care of future patients.

Racing to the Finish Line



Sprinting to the finish line of the Gator MBA 5K Run/Walk on April 26, a fundraiser to support the UF Proton Therapy Institute (UFPTI), nine-year-old Cameron Rowell ran the 5K in just over 26 minutes to become the first child to finish the race. To unknowing spectators, Cameron appeared to be an athletic, healthy boy racing to win. However, Cameron had another motive why he and his entire family were at the race that day. Cameron was a patient at UFPTI on treatment for an ependymoma, a rare type of brain tumor.

When asked why he pushed himself during the 5K, Cameron's reply was, "I wanted to win." And that, his parents say, is exactly how he lives his life.

About two months earlier, Cameron had been hit by a baseball on the side of his head during practice. He started experiencing severe headaches, nausea and lethargy, thought to be a concussion or another complication from the injury. When the symptoms did not improve, his parents took him to Fort Walton Beach Medical Center in Florida and he had a CT scan and MRI that revealed the symptoms Cameron was feeling were not from a concussion, but instead were from a grade three ependymoma brain tumor. Cameron was immediately flown to UF Health Shands Hospital in Gainesville to meet with a surgeon and underwent a successful craniotomy.

After the tumor was surgically removed, Cameron began proton radiation treatment at UFPTI in March to target any remaining microscopic cancer cells. Cameron's parents say that his spirit and attitude has been resilient throughout. "We have adopted 'Happy' by Pharell Williams as the theme song for Cameron and his adventure," said his mom. "Every time we are either on the way to or coming back from treatment, this song plays on the radio. 'Happy' reaffirms the

Community Calendar

Mark your calendar and join us when we are in a town near you.

October 2, 12 p.m.

Lake Hickory Rotary Club
Lake Hickory Country Club

430 17th Ave NW
Hickory, NC 28601

Speaker: R. Charles

Nichols, Jr., MD

October 3, 12 p.m.

Lenoir Rotary Club
First Baptist Church of Lenoir

304 Main Street NW
Lenoir, NC 28645

Speaker: R. Charles

Nichols, Jr., MD

About This Newsletter

The *Precision* newsletter is an electronic-only publication that is distributed by email. Each issue is sent monthly to patients, alumni patients and friends of the University of Florida Proton Therapy Institute (UFPTI). As the official newsletter of UFPTI, the content is compiled and prepared by our communications representative and approved by the editor Stuart Klein, executive director of UFPTI. Special bulletin newsletters may occasionally be prepared when timely topics and new developments in proton therapy occur. To opt out of receiving the email newsletter, simply [click here to unsubscribe](#). We will make every effort to remove your name from the list.

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strong fight and positivity that Cameron is putting out and I couldn't think of a better song for him."

On May 7, Cameron celebrated his last treatment by ringing "Aud's Chime" in the lobby at UFPTI. The future is certainly looking bright for this athletic superstar. Cameron is looking forward to spending the summer with his friends and his goal is to jump right back into playing baseball.

Music Therapy Program Coming to UFPTI

Thanks to your online voting and support, UFPTI has been chosen as a [Jeffrey Frank Wacks Music Therapy Program](#) site and a grant recipient of the [LIVESTRONG® Community Impact Project](#), which was created to bring proven cancer support programs to communities across the U.S. As a grantee, UFPTI will receive up to 15,600 dollars to establish a music therapy program, which will include the addition of a board-certified music therapist.

The program's overarching goal is to facilitate relaxation, decrease anxiety and stress, enhance wellness, improve pain management, and provide comfort and support for cancer patients and their caregivers. Music therapy is proven to reduce stress and pain levels associated with illness and hospitalization. For many patients, the simple act of listening to music provides a therapeutic release, promoting healing and overall well-being.

More than 100 qualified hospitals, cancer centers, university students and community organizations in seven regions across the U.S. were selected to participate in the online voting campaign that determined the award recipients. Through an 18-day online voting campaign, UFPTI was chosen as one of the 13 organizations across the country that will receive funding to replicate and implement the Jeffrey Frank Wacks Music Therapy Program.

UFPTI was previously a recipient of the 2010 LIVESTRONG Community Impact Program, which helped kickstart the artist-in-residence program. We've heard the overwhelming praise for this program and look forward to adding another offering that contributes to UFPTI's holistic approach to care.

UFPTI Community is on Facebook

Did you know that we have an online community that shares, encourages and supports those who are impacted by proton therapy? If you haven't already "liked" or don't follow our [Facebook](#) page, we encourage you to check it out. We aim to stay connected and help others stay connected with current and previous patients, caregivers, families and all other supporters. Stay in the know with events and news at UFPTI, happenings in the community, activity calendar for kids and more. All the pictures and stories from you that tag our Facebook page ([FloridaProton](#)) also appear.

We love seeing the inspiring posts and comments from the family of survivors and supporters of UFPTI and proton therapy. Stay in touch, we'd love to hear from you.

Celebrating UFPTI Staff

From personal testimonials to leading research being conducted and published to the amazing patient success stories walking the halls, UFPTI employees' commitment to excellence is on display. UFPTI would like to express gratitude to our employees for their dedication, hard work and innovative thinking, and we have officially declared **May 19-23 Employee Appreciation Week**.

Our physicians, physicists, nurses, radiation therapists, dosimetrists, research team, executive team and support staff are the ones leading UFPTI every day and helping advance proton therapy. They are passionate about what they do and are the reason why UFPTI has tremendously high success and patient approval rates. Our aim is to make proton cancer treatment at UFPTI a confident choice for those who need it most. This means that we're dedicated to delivering proton therapy in a way that takes the entire patient into account. And it takes a special group of people to help us walk the walk.

Employee Appreciation Week is an opportunity for everyone who has been touched by a UFPTI staff member to express their gratitude and share the things that make UFPTI unique. The executive team is arranging a schedule of celebratory events throughout the week. We also encourage all current and previous patients, caregivers, families and former colleagues to visit our [Facebook page](#) and share a story or picture that speaks to you and your experience at UFPTI.

Spotlight on Cancer Research

While studies and experience have shown that cancer is more treatable than ever before, more work still needs to be done. Research to understand, develop and advance cancer treatment is especially vital for radiation using protons since it is an emerging technology that is currently used in limited supply. UFPTI is dedicated to creating a strong program to set a standard of care and help further the advances of a safer and effective treatment of cancer. In honor of National Cancer Research Month, we'd like to tell you a little more about the game-changing clinical trials, protocols and studies being done at UFPTI:

Investigator-Initiated Clinical Trials: These are clinical trials that are written by our physicians. UFPTI currently has clinical trials for cancer of the prostate, breast, lung, pancreas, Hodgkin lymphoma, oligometastatic disease and macular degeneration.

Investigator-Initiated Outcomes: These are studies that are written by our physicians. For outcomes studies, there are no study interventions and all patients are treated per the standard of care. Physicians study the patients after standard treatment is complete. UFPTI currently has prospective outcomes studies for both adult and pediatric cancers of the brain/spine and cancers of the head and neck.

Cooperative Group Protocols: These are international clinical trials that are funded by the National Cancer Institute (NCI). UFPTI participates in a number of these via the Children's Cooperative Group (COG) and the Radiation Therapy Oncology Group (RTOG).

Collaborative Group Protocols: UFPTI works with other institutions on a frequent basis and currently has several joint clinical trials with St. Jude Children's Research Hospital. UFPTI also collaborates with several other proton sites on a lung trial via Proton Collaborative Group (PCG) and a pediatric outcomes study via Massachusetts General Hospital (MGH).

Research By The Numbers

- **1,034** patients are on a clinical trial – **104 female** and **930 male**.
- The oldest patient on clinical trial is **96** and youngest is **two years old**.
- **4,814** proton patients have consented to Outcomes Tracking Projects (OTP). OTP is offered to every eligible patient at UFPTI. Patients who consent to participate agree to allow the research physician to collect/consolidate information from them and their medical records regarding their disease, treatment, side effects, etc., to see what effects the radiation has on them and their

disease.

- **622** patients are on a prospective outcomes protocol.

In addition to world-class physicians and physicists, the UF Proton Therapy Institute has a dedicated research staff that works every day to expand the power of proton therapy:

Amanda Prince, RN, BSN, CCRP

- Assistant Director/Research Manager
- Work experience with oncology research since 1999

Chris Morris, MS

- Statistician and VTOC liaison
- Work experience with oncology research since 2001

Robin Toton, RN, CCRP

- Lead Project Manager – Prostate, Oligometas
- Work experience with oncology research since 2009

Valerie Fergusson, RN, OCN, CCRP

- Project Manager – Pancreas, COG, OTP, Sarcoma, GYN, Dosimetry
- Work experience with oncology research since 2006

Ashley Williams, BA, CCRP

- Project Manager – Breast, Lymphoma, Lung, St. Jude
- Work experience with oncology research since 2010

Rochelle Carver, RN, BA, CCRC

- Project Manager – Adult CNS, Eye, Lung, H+N, St. Jude
- Work experience with oncology research since 2010

Jackie Causer, RN, BSN,BSH

- Project Manager – PPCR, Pediatrics (non-COG/St Jude)
- Work experience with oncology research since 2013

Meagan McCall, BS

- Program Assistant on prostate-related projects

Brittany Lomax, BS

- Research Associate

In recognition of National Cancer Research Month, UFPTI would like to thank all the specialists and supporters of proton therapy.

Cancer Awareness Spotlight

National cancer awareness campaigns aim to increase awareness of symptoms, encourage prevention and detection, support patients, caregivers and families, and save lives. This May, there are two campaigns for cancers treated by UFPTI: melanoma and brain tumors.

Melanoma

Melanoma, or skin cancer, can appear in several forms over a person's body. However, many people don't realize that melanoma can also appear in the eye. Melanoma of the eye is the most common type of cancer that develops within the eye, but it is still fairly rare.

Often melanomas of the eye are found during a routine eye exam.

When the doctor looks through the pupil at the back of the eye, he or she may be able to see a dark spot that might be an early melanoma.

Because the eyes are surrounded by such important structures and vulnerable tissues, it's important to treat cancer of the eye with radiation that can be carefully controlled. Since proton radiation is more easily manipulated than conventional radiation, oncologists can deliver powerful doses of proton therapy to the tumor site and minimize damage to surrounding tissues in the eye and head. With protons, the patient typically receives four targeted radiation doses that avoid critical structures around and within the eye.

While a rare form of cancer, melanomas of the eye are one of the most common cancers treated with proton therapy due to the more controlled nature of the treatment. Eye cancer patients treated with protons have a 90 to 95 percent chance of local control of the cancer and an eye retention rate of approximately 85 percent.

The types of cancer of the eye treated with proton therapy are:

- Intraocular melanoma
- Choroidal metastasis
- Retinoblastoma
- Choroidal hemangiomas

Brain Tumors

Primary brain tumors include a wide variety of tumors that arise from the tissues of the brain, or the brain's immediate surroundings. Brain tumors are typically named for the type of cell from which they originate and are categorized as either glial (composed of glial cells) or non-glial in origin (arising from structures in the brain such as glands, nerves, blood vessels or the meninges, a thin membrane which envelops the brain and spinal cord). Similarly, brain tumors may be grouped as being either benign (nonmalignant) or malignant (cancerous).

Treatment of primary brain tumors commonly involves surgery to remove as much of the tumor as possible. However, most brain tumors are not cured by surgery alone and require radiation therapy to eradicate the remaining stray cancer cells. Radiation therapy alone may also be an option when surgical removal of the tumor is not feasible and the addition of chemotherapy may also be indicated in some cases.

While a large proportion of brain tumors are benign (nonmalignant), intervention and treatment is still necessary as these tumors can cause significant health issues. Contrary to benign tumors in other parts of the body, which uncommonly cause major health problems, benign brain tumors can lead to significant injury to surrounding brain tissue by causing swelling and applying pressure on the brain as well as inside the skull.

Like eye cancers, proton therapy offers significant advantages in the treatment of brain tumors. The brain is very sensitive to radiation, which can lead to significant side effects if normal brain tissue receives a large dose, especially if the patient is very young. Moreover, these tumors are often located nearby very delicate and vitally important tissues and structures. With proton therapy, highly precise beams of protons eliminate the "exit doses" characteristic of traditional radiation treatments, so the protons target only the site of the brain tumor, sparing surrounding healthy brain and vital structures. As a result, proton therapy can considerably reduce the amount of healthy brain that receives radiation, decreasing your risk of cognitive decline and neurologic deficits. Proton therapy may also significantly reduce the radiation dose to the optic pathways, glands, and inner ear, thereby reducing the risk of visual impairment, hormonal deficiencies and hearing loss.

Brain tumors treated with proton therapy include:

- Low-grade gliomas
(Astrocytoma, Oligoastrocytoma, Oligodendroglioma)
- Ependymomas
- Pineal tumors
- Embryonal tumors (Medulloblastoma, CNS primitive neuroectodermal tumor (PNET), Atypical teratoid/rhabdoid tumor)
- Sellar tumors (Pituitary tumors, Craniopharyngioma)
- Meningiomas

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