

Precision

September 2013



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

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Message from Stuart Klein, Executive Director

Health Insurance and Coverage of Proton Therapy for Prostate Cancer



Last month proton therapy was in the news because two insurance companies announced they would no longer cover proton therapy for early prostate cancer treatment. According to the news reports the decision was based on cost.

They cited a flawed study that concluded proton therapy produced the same results as a lower cost method of radiation therapy called IMRT. The two insurers reasoned that if the same results can be achieved with a cheaper method, then it was no longer necessary for insured members to have proton therapy as a covered treatment option.

A fair review of the available clinical data clearly points to the superiority of proton therapy for treating prostate cancer. Moreover these data are based on actual patient outcomes that are reported by physicians and by patients.

Our published data show that at two years after treatment 99 percent of patients have no cancer and have very low rates of treatment-related side effects – a 1.9 percent rate of urinary complications and a .05 percent rate of bowel complications.

Longer-term data from Harvard show that at five years after high-dose proton therapy 91.3 percent of prostate cancer patients have no cancer and have very low rates of treatment-related side effects – a 2 percent rate of urinary or bowel complications.

Medicare and most insurance companies continue to cover proton therapy for prostate cancer at any stage of the disease. The largest radiation oncology medical society has voiced support for coverage of proton therapy for prostate cancer. In a March 13, 2013, statement, the American Society of Radiation Oncologists (ASTRO) said “ASTRO strongly supports allowing for coverage with evidence development for patients treated on clinical trials or within prospective registries.”

For an insurer to rule out coverage of a proven, life-saving treatment because of cost without first attempting a customary reimbursement rate negotiation with the provider shows a lack of due process at best and carelessness at worst.

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.

Community Calendar

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

January 8, 2014, 1 p.m.

West Jax Rotary Club
Quality Inn
I-295 at Commonwealth
Ave.

Jacksonville, FL

*Speaker: R. Charles
Nichols, M.D.*

If you would like a speaker to come to a group in your area, [click here to send us an email.](#)

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

UFPTI abstracts selected for presentation at ASTRO 2013 annual meeting

This month, UFPTI physicians will present clinical outcomes data at the premier radiation oncology conference -- ASTRO 2013 Annual Meeting. Among the disease sites selected for presentation are prostate, lung, breast and brain. A total of 12 proton therapy studies will be presented.

Significantly, UFPTI will present five-year outcomes of prostate cancer patients, a study on the safety of proton therapy in children with tumors of the brain and skull base, early outcomes of Hodgkin lymphoma patients, and a pilot study of breast cancer patients, among others.

Bieber mania hits UFPTI

Justin Bieber is no stranger to making tweens' and teenagers' hearts pound a little faster. When UFPTI learned that the singer was going to be in Jacksonville, we reached out to SMG, a management company for events in Jacksonville. Through our relationships and SMG's relationships, they were able to donate 16 tickets plus parking passes to the Justin Bieber concert. That would have been gracious enough, but SMG went further. They reached out to Pepsi, a cookie company and other businesses to host a pre-concert party for all children medical patients associated with UF Proton Therapy Institute, Make a Wish Foundation, Wolfson's Children Hospital, and more. When it was all said and done, five families with children under treatment for cancer had one great experience at the Justin Bieber concert. We would like to thank SMG and the people who donated the tickets for their charity.

Seb James makes music

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Sebastian James, a 22-year-old from England, recently completed proton therapy for a rare tumor in his nasal sinuses. Even though he had proton therapy twice a day, he managed to make music performance a priority during the seven weeks he was in Jacksonville. A singer/songwriter/guitarist, Seb participated in open-mic nights at several locations around town and made friends with Jacksonville musicians. "This is what's motivating him to keep on with treatments is performing," said his mother, Sue Latham.

As a celebration of completing treatment, Seb's friends and fellow members of the band Callow Saints came to Jacksonville to visit and

to perform. Patient services director Bradlee Robbert made arrangements for a special concert to take place in a nearby lecture hall at UF Health. More than 75 people – UFPTI patients, spouses, staff and community members – enjoyed the band’s U.S. debut. Click [here](#) to watch a portion of the performance.

“I was very impressed,” said Dr. Robert Malyapa, Seb’s radiation oncologist at UFPTI. “He has gone through a lot – chemo, surgery, more chemo and now radiation. And now, just three days after completing treatment, he’s off the pain meds and continuing to play music.”

Seb needed proton therapy to kill any possible cancer cells that may have been missed during surgical removal of the tumor, a procedure that also removed his right eye. According to Dr. Malyapa, by using protons, he was able to deliver radiation to the tumor bed while sparing vision in Seb’s left eye and avoiding damage to his brain. “He has done very well,” said Dr. Malyapa.

Seb was complimentary of the staff and physicians at UFPTI, saying it was refreshing to meet such nice people who were really engaged with him on a professional and personal level. “The doctors here have been fantastic. They are on top of everything,” he said. He encourages other people fighting cancer to stay positive. For Seb, music was his way to express himself and to keep focused on the good things in life.

Prostate follow-up clinics

In seven years, UFPTI has had the privilege of treating and caring for more than 3,000 men with prostate cancer. We have seen wonderful results from the proton therapy treatments. Typically we like to have follow-up appointments with our alumni prostate cancer patients post treatment at six months, one year and annually each subsequent year. This allows UFPTI to give the best possible continuum of care. It also allows for UFPTI to meet one of our mission statements: “To gather medical data and conduct clinical research.”

To meet the needs of our alumni patients, UFPTI has created a novel follow-up appointment that encourages fellow patients, staff and physicians to reconnect. Six times a year UFPTI conducts a prostate cancer follow-up clinic in Jacksonville that includes an entertaining and educational schedule of events. More than 200 alumni patients meet one-on-one with their physician and also attend their choice of activities arranged for the alumni and their guests during the two-day event.

Attendees gather for lunch along with current patients and caregivers at the Crowne Plaza Hotel conference room. During the lunch, the room is filled with laughter and warmth created by the energy of happy alumni patients. Following a lunch filled with activities, we have physician presentations. These educational presentations have covered topics about prostate cancer treatments and prevention, quality of life post-treatment and other cancers treated with protons.

We cap off the evening back at UFPTI for a relaxing night of hors d'oeuvres and music in our art gallery.

The remaining clinics for 2013 are: October 17, and December 5.

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2015 North Jefferson Street
Jacksonville, FL 32206