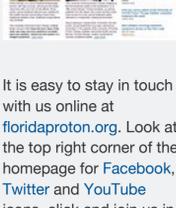


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## IN OTHER NEWS

### Keep In Touch



It is easy to stay in touch with us online at [floridaproton.org](http://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.

## Community Calendar

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

### December 4, 12 – 4 p.m.

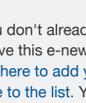
Prostate Cancer Follow-Up Event  
Crown Plaza  
Jacksonville Riverfront Hotel – Main Ballroom  
1201 Riverplace Blvd.  
Jacksonville, FL 32207  
Speakers: Nancy Price Mendenhall, MD, & William M. Mendenhall, MD

## 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 Health Proton Therapy Institute. As the official newsletter of the Institute, the content is compiled and prepared by our communications representative and approved by the editor Stuart Klein, executive director of UF Health Proton Therapy Institute. 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.

If you would like to send a Letter to the Editor, [please click here](#).

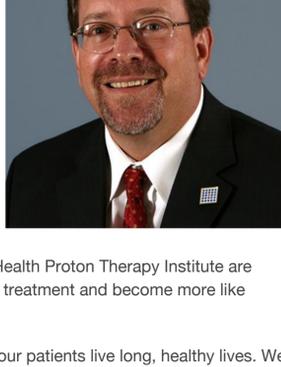
## Sign-Up Today



If you don't already receive this e-newsletter, [click here to add your name to the list](#). You will also be notified of any future events in your area.

## Message from Stuart Klein, Executive Director

The importance of establishing and building trust is a foundation for creating lasting and meaningful relationships. Our patients at the UF Health Proton Therapy Institute trust that we will do our utmost to help them deal with their cancer. This level of trust is essential and guides us in our daily activities. I'm proud to say that I've personally heard from countless patients that the relationships formed at the UF Health Proton Therapy Institute are ones that go above and beyond treatment and become more like family.



Our number one goal is to help our patients live long, healthy lives. We thank you for trusting us and promise that we will continue to do everything we can to advance the effective treatment of cancer. We hope you will join us and help spread the word about the positive benefits of proton therapy so that more people can understand and realize a better quality of life after cancer.

Sincerely,

Stuart Klein

## Survivor Spotlight: Kathleen Patti



At seven years old, Kathleen was diagnosed with cancer and underwent surgery and traditional radiation to remove the tumor located along her spine. The treatment was successful and Kathleen went on with her life as any normal little girl would. However, children are especially vulnerable to various modalities of treatment as their healthy tissues are still rapidly growing and the effects of treatment, particularly radiation, are magnified.

When Kathleen was in eighth grade, she found out that her initial radiation had caused a rare secondary rhabdomyosarcoma tumor that wrapped twice around her spine.

"It was tough and scary," said Kathleen. "But, as a kid and teenager, I think we do have a little bit of a different outlook on the situation. We're still kids and we'll still find ways to goof off – even if we do have cancer."

Because of the rare location of her tumor around her spine as well as the reoccurrence from her previous treatment, Kathleen was referred to a regimen of nine months of chemotherapy and proton therapy.

"When you get your first chemo treatment, it's like the worst thing ever. It was such a relief when I started at the UF Health Proton Therapy Institute and found out that this really wasn't that bad. It was nice and I actually felt great. It didn't hurt, I got to take a nice nap every day and drink lots of hot chocolate," said Kathleen.

Kathleen, now four years cancer free, recently graduated high school, was prom queen and is now just beginning her college career and enjoying the next phase of her life. For her, two rounds of cancer wasn't something to fear, but rather to overcome.

"It helps enhance you as a person. I can't imagine my life without cancer," said Kathleen. "It really made me the person I am today. I wouldn't be me if it hadn't been for the people I met and the things I went through."

"I want kids who are going through cancer to know that it's not necessarily the end of the world. It seems like it at times, but you can do it. For people out there who have a friend with cancer, my advice is to just be there for them. They're ordinary people just like you, so just treat them like a regular person. Because even though they're going through something extraordinary, it doesn't mean they don't want to be normal too."

## The Truth About Proton Therapy

It may not come as a surprise that many of our patients have never heard about proton therapy before visiting and are referred either by research of their own or by word-of-mouth. That being the case, there have been recent reports and rumors about proton therapy that aren't accurate or factual. We are so fortunate to have a close-knit family of survivors and want to ensure you have the information and tools you need to answer any questions you may receive about protons. We have developed a [website](#) dedicated to facts about protons that you can use as a resource.

For patients facing many types of cancer, including breast, prostate, lung, esophagus, head and neck, skull base, liver, lymphoma, sarcomas, etc., proton therapy offers an effective alternative to traditional radiation. The targeted, precise beam allows radiation to kill cancer but spare healthy tissue surrounding it. This also reduces the risk of side effects and secondary cancers when compared to other forms of radiation. Because of this precision, proton therapy is recommended for people of all ages from toddlers to those young at heart.

The cost of proton therapy and proton therapy centers has received some amount of scrutiny over the years. While we believe there is not a price tag that you can put on quality of life, recent advances in design, refinements in technology and smaller machines are leading to a reduction in the cost to build and operate a state-of-the-art proton therapy center. While it is not inexpensive, it doesn't cost nearly what it once did when the technology and design was brand new. Currently, there are 15 proton therapy centers in the U.S. and 50 in the world.

From a cost perspective, proton therapy initially may be more expensive than traditional radiation, depending upon the complexity of the case; however, the total costs of medical care for a proton therapy patient may be lower than with traditional radiation because short-term and long-term side effects are often minimized or avoided. These side effects can be costly to treat as well as physically devastating to patients.

As for coverage, both private insurers and Medicare cover proton therapy as treatment for various types of cancer. Because of recent actions by a handful of companies, there have been some reports that have falsely stated that protons are no longer widely covered. Health insurance companies evaluate treatments for cancer on a case-by-case basis and may vary depending which policy is chosen. However, a majority of cases we treat at the UF Health Proton Therapy Institute are covered for the individuals. For a list of cancers treated, you can visit our website. In addition, we have full-time staff who are available to discuss coverage and finances to ensure there are no financial uncertainties for anyone interested in and qualified for proton therapy treatment.

While technology is advancing and more proton centers are being planned, others that have been around for several decades have recently been in the news for their decision to close. While the decision was made based on several unique factors, the benefits of proton treatment were not among them. In fact, the first facility in the U.S. to treat tumors using proton beam radiation reestablished itself after its closing and is thriving today.

Again, our patients and caregivers are our biggest supporters as you have been through and understand proton therapy as it relates to your case. If there are specific questions you have about recent news reported about proton therapy or if you're asked a question and aren't sure of the accurate response, please contact us. We want to make sure you feel confident if anyone comes up to you and asks about protons and your experience. For more information, you can also always visit our website [FloridaProton.org](http://FloridaProton.org), call us toll free (877) 686-6009 or check [FloridaProtonFacts.org](http://FloridaProtonFacts.org).

## Lung Cancer Support Group

The American Lung Association in Northeast Florida has teamed up with the UF Health Proton Therapy Institute to host a re-occurring free workshop for people interested in and/or affected by lung cancer. The workshop, called "Frankly Speaking About Cancer: Lung Cancer," will cover the latest treatments for lung cancer. Expert panelists will be available to answer questions about lung cancer as well as discuss side effects, side effect management, and tools to overcome the social and emotional challenges of the diagnosis.

There was a fantastic group that showed up for the inaugural meeting last Thursday, Nov. 6, and was facilitated by Dr. Bradford Hoppe. The group will continue to be held every other month on the first Thursday of the month (with the exception of January since it's New Year's Day.) The next meeting is scheduled for January 8 and will also be held at UF Health Proton Therapy Institute.

For more details and registration, call Beth Jensen at (904) 520-7117 or visit [cancersupportcommunity.org](http://cancersupportcommunity.org) and [lung.org/florida](http://lung.org/florida).

## Love Conquers All



For their second wedding anniversary, Mark and Kerry Kelso decided to renew their wedding vows in true American Halloween fashion. The couple, from the U.K., has been in the U.S. for Mark's treatment for chordoma.

The Kelso's described the first couple years of their marriage as a whirlwind. They had just found out about the tumor in Mark's brain nine months into their marriage, had a baby on the way, just started a new job and moved into a new house the day before the diagnosis. However, as they look back and smile at each other, it's clear they are still going strong.

"This is a chance for us to hit the restart button. It's a new lease on life," said Kerry.

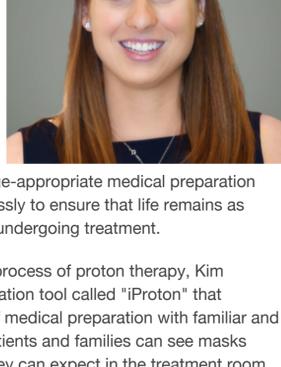
As for the Halloween theme, Mark and Kerry agree that they wanted to do something fun to celebrate the occasion.

"We'd like to thank everybody at the UF Health Proton Therapy Institute. All the staff and other patients have been amazing. Being thousands of miles away from home, this has felt like home from day one. We've made many new friends along the way – friends that feel like family," Mark and Kerry said.

And it's evident that the sentiment is shared as the UF Health Proton Therapy Institute's lobby was filled with costumed staff, patients and previous patients who came from hundreds of miles away to celebrate this special day with the couple.

## Health Care Hero

Congratulations to Kim Ely, UF Health Proton Therapy Institute's child life specialist, for being named a 2014 Health Care Hero by the *Jacksonville Business Journal*. With the largest pediatric proton program in the world, Kim plays a large role within our facility and an even larger one in the lives of patients and families. Through play, self-expression activities and age-appropriate medical preparation and education, Kim works tirelessly to ensure that life remains as normal as possible for children undergoing treatment.



To familiarize patients with the process of proton therapy, Kim developed an interactive preparation tool called "iProton" that combines the known benefits of medical preparation with familiar and non-threatening technology. Patients and families can see masks being made, listen to sounds they can expect in the treatment room as well as see the process of a real patient being prepared for treatment. Kim also combines this with medical play utilizing "me dolls" to help even our youngest patients grasp the process required for treatment through all their senses – from the touch of gloves to the smells of the mask and the sounds in the room. Through the "iProton" program, and an in-depth tour of the facility, patients have the opportunity to reflect on fears and misconceptions of treatment and develop coping strategies before treatment, so nothing is unfamiliar.

To encourage normal development and a sense of fun, Kim has also developed Family Fun Night every other Thursday night. Dinner is provided followed by a rotation of community activities, like Disney bingo, pottery painting, zoo visits and "mad science" shows.

Not only have her methods helped hundreds of previous patients cope with the stress, anxiety and uncertainty of illness and treatment, Kim has helped lower the rate of children ages five to seven requiring daily anesthesia for treatment from 94 percent to 50 percent. From all of us at the UF Health Proton Therapy Institute, we thank you, Kim, for all that you do to continue to advance the care and treatment at our facility. Congratulations on your award.