

TABLE OF CONTENTS

- **Message from Stuart Klein, Executive Director**
- **Children fighting cancer inspire Brotherhood to establish fund**
- **Triathlete, proton alum competes for shot at world championship**
- **Proton alumni participate in local health fair**
- **Road trip to raise proton therapy awareness, funds**
- **Cancer Awareness Spotlight**

IN OTHER NEWS

Keep In Touch



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.

Community Calendar

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

August 13, 6:15 p.m.

Man to Man, Beaches
 Wilson Cancer Care
 Center
 1375 Roberts Dr.
 Jacksonville Beach, FL
 Speaker: *Randal
 Henderson, M.D.*

Sept. 6, 9:30 a.m.

Fairfield Glade
 Conference Center
 Fairfield Glade, TN
 Speaker: *TBD*

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

Message from Stuart Klein, Executive Director

Our proton graduates are among the most motivated, generous, action-oriented cancer survivors. Time and again we hear of outreach, advocacy and fundraising efforts solely coordinated by our alumni. We are heartened to hear their stories – how they tell people who could benefit from the treatment about proton therapy, how they spend their personal time and energy to raise funds to donate to the treatment of others. I hope you will enjoy reading about a few of the remarkable initiatives in this month's *Precision*.

Sincerely,
Stuart Klein



Children fighting cancer inspire Brotherhood to establish fund



A young boy dressed in a Cub Scout uniform sat with his mom in the main lobby of UFPTI. He was being treated for a brain tumor and was there for daily proton therapy. He didn't usually wear his uniform to treatment, but this day was special. He was going to be part of his Cub Scout Pack's meeting back home via Skype. One of the adult patients who had become a mentor to the boy watched the laptop screen alongside him as his friends removed their Cub Scout caps. One by one they shaved their heads as an act of support for their friend who had lost his hair during cancer treatment.

Dave Powell, a prostate cancer patient (March 2011) from Stuart, Fla., was the adult watching. He was so moved by the meeting and by the many conversations he had with parents and their children throughout treatment, he was determined to do something to help.

Dave and four other men who had formed a friendship during the Brotherhood of the Balloon (BOB) prostate cancer support meetings and other organized social activities at UFPTI coordinated a March Madness basketball challenge to raise funds to buy iPads for use in the pediatric program. The success of this first fundraiser launched an ongoing initiative called the BOB for the Children Fund.

"We wanted to turn the fear that we saw in the kids, the uneasiness in the parents' eyes, into something more positive," said Dave, chairman and co-founder of the BOB for the Children Fund. "We were all having fun and these kids should have fun, too." Dave and the other founders, Richard Brandenburg, Michael Wilson, John Bankston and Kurt Menger, wanted to see the children and their families experience the same sort of camaraderie that the BOB members experienced. The men envisioned support group gatherings for the parents, outings for the children and families and other activities that would help lift their spirits and ease their burdens.

Together with the pediatric team at UFPTI, the BOB for the Children Fund founders created a wish list of projects that could provide comfort and relief to children and their families.

Through fundraising appeals to UFPTI alumni, BOB members, adult patients and the community, the BOB for the Children Fund helps make the following six pediatric program initiatives possible:

1. Child Life Specialist – uses knowledge of child development and developmentally appropriate interventions to promote effective coping through play, preparation, and education during difficult tests, procedures and various types of treatments.
2. Artist-in-Residence – leads children, their siblings and families in a variety of hands-on art projects to help occupy them as they wait for treatment.
3. Van Transportation – a dedicated driver and multi-passenger van transports families to and from the facility.

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.

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.

4. Family Support – Family Fun Night is facilitated by professionals in social work and child life departments and offers an opportunity for pediatric patients and their families to socialize and support one another. Following dinner, hands-on entertainment is provided to normalize their lives away from home.
5. Personalized Blanket & Gator for each child – a colorful blanket to keep them warm during treatments and a stuffed UF Gator to provide comfort.
6. iPads – Combining an array of custom videos and real sound effects with puzzles and games on the iPad, our child life specialist has designed and created an interactive preparation tool that enhances the planning and rehearsal skills required for successful delivery of proton therapy. For example, in some sessions, patients are shown videos of other patients having treatment masks made, while in other sessions, patients are exposed to the intimidating audio sounds that they may expect during treatment.

Dr. Danny Indelicato, who directs the pediatric program, recently described the value of the fund for children and families served at UFPTI. "Approximately 90% of the children treated at the UF Proton Therapy Institute come from outside Jacksonville. In fact, the majority travel over 100 miles from their home to seek the specialized care offered here," Dr. Indelicato said. "These families receive the diagnosis of a child with cancer. Then they undergo surgery, perhaps chemotherapy. Then they are told they must pick up and leave their home, their friends, their jobs, their school, their church, their whole support network and travel to Florida for therapy they cannot receive at their local hospital. For 2 months, their world – already turned upside down by the diagnosis of cancer – is subject to even more upheaval. This impacts everyone: The child with cancer, the siblings, and the parents."

Dr. Indelicato explained that UFPTI has an obligation that far exceeds the technical delivery of proton therapy. "We must sustain these families through these critical months in Jacksonville. This is a time of immense need. Medical support, psychological support, and social support are not isolated needs. They are interrelated and dependent. Nowhere is this concept as clear as in our youngest patients." In this perspective, Dr. Indelicato echoes principles that have guided patient care at UFPTI since its very inception. These are the same ideals that resonated with Dave and the other founders of the BOB for the Children Fund.

UFPTI executive director Stuart Klein acknowledged the contributions the BOB for the Children Fund and founding members have made to the benefit of pediatric patients. "It's really made a big difference in the quality of life for the patients and for the quality of the program." UFPTI is currently the biggest pediatric and adolescent proton therapy program in the world, serving over 140 children in 2012. The growth and scope of the program is a reflection of care that considers every aspect of support. And it could not be possible without the generosity of the donors to the BOB for the Children Fund.

Dave encourages adult patients to spend some time with the families and children to learn more about them, to lend a sympathetic ear and to provide support through the BOB for the Children Fund. To learn more or to make a contribution, visit www.bobchildrenfund.org.

Gifts can also be made via check by noting BOB for the Children Fund in the memo and mailing to the attention of development director Linda Sackett at UFPTI, 2015 N. Jefferson St., Jacksonville, FL 32206. Those who would prefer to make an annual pledge can contact Linda at (904) 588-1462 or (904) 874-5808. Every contribution makes a difference and 100 percent of contributions benefit the UFPTI pediatric proton program.

Triathlete, proton alum competes for shot at world championship

Being a triathlete is a feat of strength, endurance and will for even the most physically fit people. So it is inspiring to hear the story of 43-year-old Todd Varney, UFPTI alum 2012, who first overcame obesity and now is a prostate cancer survivor preparing for the 2013 Ironman World Championship in Hawaii.

He created a video describing how he lives the Ironman mantra "Anything is Possible" and submitted it into the Kona Inspired competition for a chance to win an entry into the championship event. [See the video here](#).

In an email, Todd said, "It is humbling to put this type of video out to the public, but my goal is to raise awareness for folks who feel that their problems cannot be overcome. If I am selected, I will also be doing some awareness and fundraising for the Shands/UF Proton Center, with funds allocated to help cover costs for those without adequate coverage."

The first round of public voting ended prior to the publication of this e-newsletter. However, 45 finalists will be announced starting May 14. We are hopeful that Todd will be among the finalists. He will need our votes to reach the winner's circle. Check this [link](#) or the [UFPTI Facebook page](#) for updates.

Proton alumni participate in local health fair

By: Bradlee Robbert, patient services director

We hear quite often from patients that they want to be advocates to tell people about proton therapy once their treatments are completed. We are humbled by the amount of new patients who schedule appointments with UFPTI because of our patients' endorsements. Most patients will tell their civic groups, local friends and family or fellow employees about



proton therapy.

A remarkable group of alumni took advocacy to the next level and hosted a booth at a health expo in their community. Tom Bomkamp, Peter Kraslawsky, and Thomas Zuraf attended the StayinTV Health and Services Event in Tellico Village, Tenn., near Knoxville on April 12. These gentlemen went above and beyond trying to get the word out about prostate cancer awareness, cancer support, and treatment options.

They also have created a support group, "East Tennessee BOB Group" for all current, past, and potential prostate cancer patients. This cancer support group meets once a month and currently has about 50 members. If you are interested in contacting the "East Tennessee BOB Group," please email Peter Kraslawsky at ifundem@charter.net. Thank you for your continued support of proton therapy.

Road trip to raise proton therapy awareness, funds



UF Proton Therapy Institute alumnus Rui Dos Santos (April 2012) has a unique recipe for giving back and he invites others to join him.

- One 1984 Mercedes turbo diesel
- One vegetable oil conversion kit
- One "bucket list"
- One worthy cause – Pediatric Proton Program at UFPTI

While he was a patient at UFPTI he was touched by the many children and young parents he saw in the waiting room. He imagined himself in their shoes. Young parents dealing with their child's life-threatening illness, the emotional stress and financial strain that they must be going through. "I thought there must be something I could do for the children. Their families. Something to ease the burden whether it's money for a rental car or meals, something."

He decided he wanted to raise money for the pediatric proton program. A handyman by profession, he has combined his passions for the environment and protons and has converted a 1984 Mercedes turbo diesel to run on vegetable oil. He plans to take a 13,000-mile trip in "the Deep Fryer," as he calls it, around the four corners of the continental U.S. this summer – a trip he has always wanted to take. Starting at mile-marker 0 of A1A in Key West, Fla., he will drive through Florida and head west to San Diego, north to Seattle, then east to Maine and south to Florida.

Along the way, he plans to raise awareness about proton therapy and raise money for the pediatric proton program. He is taking pledges via his website www.frenchfryconnection.com.

He plans to travel 800-1,000 miles per day and to complete the trip in two weeks this August.

Going along on the trip will be three people, including his 20-year-old son Justin. "He's always got a project going," said Justin. "This is the first time he's taken up a cause like this, though."

In fact, Rui has a history of taking on projects, and some of them are extraordinary acts of generosity. One act of generosity 25 years ago actually led to a special meeting in the UFPTI lobby last month.

When he was 25 years old, Rui was hired to repair the air conditioner at the home of an 86-year-old man named John who swam every day and worked out at the gym three times a week. "He lived in Briny Breezes, a trailer park on the beach, four trailers from the Atlantic Ocean," Rui described. "He wouldn't pay for his invoice until I arm wrestled him." According to Rui, he finally agreed to the unusual challenge and it turned out to be quite a challenge, but in the end, Rui won the wrestling match.

From that day on, Rui and "Uncle John" were friends. Rui took on the role of caregiver as Uncle John advanced in age and was unable to drive. Eventually, Rui built an addition onto his home so Uncle John could come live with him and his young wife and children. When Uncle John passed away at age 97, Rui was in touch with Uncle John's next of kin, a nephew named Peter who lived in New York.

Over the years, Rui and Peter have stayed in touch, but have never met in person. Last Christmas, Rui was updating Peter about what was going on in his life, including having prostate cancer and treatment. Peter said that he had just been diagnosed with prostate cancer and was waiting for biopsy results. Rui urged Peter to look into proton therapy as he considered his treatment options.

Peter ended up deciding to have proton therapy at UFPTI. Last month, Rui drove up from his home in West Palm Beach for his annual checkup. Peter was in his final week of treatment. On April 24, the two men met in person for the first time in the main lobby of UFPTI.

Look in future issues of *Precision* and on the [UFPTI Facebook page](#) for updates on Rui's road trip.

May is brain tumor awareness month. According to the Central Brain Tumor Registry of the United States, an estimated 69,720 people in the U.S. will be diagnosed with malignant or non-malignant brain tumors in 2013.¹ A brain tumor is a type of cancer that originates in the tissues of the brain or the central nervous system (CNS). Regardless of malignant or non-malignant diagnosis, brain tumors require intervention since they usually severely impair the individual's health both biologically and cognitively. Most patients receive a combination of surgery, radiation and chemotherapy.

Proton therapy is often used to treat the region where a tumor has been surgically removed (resected) in an effort to destroy any stray cancerous cells and give the patient the best chance for a cure. In many cases, proton therapy is the only treatment option when tumors of the brain cannot be resected safely.

Proton therapy offers the ability to minimize unnecessary radiation to healthy portions of the brain and CNS and surrounding critical structures such as the eyes and ears. For tumors located in the spine, proton therapy can deliver optimal radiation doses with minimal risk of damage to the heart, lungs, digestive tract and reproductive organs. For cancer survivors this may mean a reduced risk of developing a secondary cancer later in life. In pediatric patients, by minimizing radiation to the normal brain tissues and other organs, proton therapy may limit side effects like reduced IQ and heart disease.

UFPTI has several **clinical trials for brain tumors** in adults and children. Ongoing research at UFPTI aims to add to the data known about the effects of proton therapy in the treatment of brain and CNS tumors.

Brain tumors currently treated at UFPTI include:

- low grade gliomas
 - o astrocytoma
 - o oligoastrocytoma
 - o oligodendroglioma
- ependymomas
- pineal tumors
- embryonal tumors
 - o medulloblastoma
 - o CNS primitive neuroectodermal tumor (PNET)
 - o atypical teratoid/rhabdoid tumor
- sellar tumors
 - o pituitary tumors
 - o craniopharyngioma
- meningiomas
- tumors of skull-base: chordoma and chondrosarcoma

1. Fact Sheet. Central Brain Tumor Registry of the United States. Retrieved May 1, 2013.
<http://www.cbtrus.org/factsheet/factsheet.html>