

November 24, 2014

Someone to talk to...  
who understands!



Us TOO International  
Prostate Cancer Education  
& Support Network

**OUR MISSION**

*Be the leading  
prostate cancer organization  
helping men and their families  
make informed decisions  
about prostate cancer  
detection and treatment  
through  
support, education and advocacy.*

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Dear Friends of Us TOO and Chapter/Support Group Leaders,

I hope that this delivery of the [December 2014 issue of the HotSheet](#) finds you doing well and looking forward to the holiday season!

As we wrap up November, designated as men's health awareness month—A.K.A. "Movember," we'd like to pass along an article spotlighting some of the work of long-time Us TOO support group leader, former Us TOO board member, and Director Emeritus **Jim Kiefert**. He's been effectively managing his prostate cancer for more than 25 years while enjoying a very active lifestyle. Thank you, Jim, for all that you've done and continue to do for Us TOO and the prostate cancer community at large. To [read the article CLICK HERE](#).

Earlier this month we launched the [new Us TOO website](#) at [www.ustoo.org](http://www.ustoo.org). It retains all of the information found on the former website and features a more user-friendly experience with an intuitive navigation path to access most content within two levels or "clicks." The main page provides multiple opportunities for visitors to immediately **take action and get connected** to information and resources for making informed decisions about prostate cancer detection and treatment through support, education and advocacy. A new feature on the website is [interview excerpts from Prostate Forum \(CLICK HERE\)](#). As with any vital website, updating the content will continue to be an ongoing process. We invite you to visit the new website and share your feedback.

I was in Washington, DC, November 3rd through 6th attending the **NCCN conference on patient issues** surrounding data, access and palliative care; and the **NCCS Cancer Roundtable** to discuss communicating care cost, Medicare data release, physician payments Sunshine Act, transparency in relations between patient advocacy organizations and corporate funders, updates on ACA/Obama care and enhancing the sharing of patient research data. Chuck was also in DC to attend the **cancer policy advocate training seminar**, compliments of the National Coalition for Cancer Survivorship (NCCS).

Last week I was in Seattle at Dendreon's headquarters and research center attending an advocacy summit meeting. Although **Dendreon is filing for Chapter 11** bankruptcy protection, we were very pleased to hear that the company plans to continue operations during the restructuring **and will continue to provide Provenge® (sipuleucel-T) to prostate cancer patients**. Watch for a statement being developed collaboratively from all of the advocacy groups who were in attendance at the meeting.

Terri, Chuck and I were in Sarasota on the 20th for the **Us TOO Regional Leadership Town Hall Meeting**—our seventh in the past few years. Thank you to event sponsors Dendreon, Sanofi, Endo, Takeda/Millennium, and Pints for Prostates; and to host Ginya Carnahan with the Datolli Cancer Center & Brachytherapy Research Institute. The meeting provided a valuable opportunity for advancing collaboration among chapters, support groups and the Us TOO home office as we welcomed former ACS Man to Man support groups into the Us TOO network and mapped the plan for growing the Us TOO Southeast Region chapter and affiliated support groups.

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Us TOO is a 501(c)3 non-profit organization founded in 1990 by prostate cancer survivors and their families.



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We're also busy preparing for the **Us TOO board meeting on December 5th and 6th** in Chicago. We're especially excited about the agenda for this meeting since it includes the presentation of the **Edward C. Kaps HOPE Awards**. This year's recipients will be announced later this week.

The New Year is getting very close and the highlight of 2015 for Us TOO will be **our 25th Anniversary Celebration & Educational Symposium!** Please note that the event date was tentatively scheduled for April but has now been confirmed for **June 19th and 20th**. Mark your calendars and plan to join us in Chicago!

Us TOO and ZERO are hosting a **free educational webinar, "Prostate Cancer and Bone Health,"** to address bone-related complications resulting from prostate cancer. It's today—Monday, November 24th, at 3:00 pm ET. To get more information and register [CLICK HERE](#).

If you haven't already done so, please **support our "Thanks and Giving" holiday campaign** with a donation to Us TOO to help fund support services, education resources and advocacy/awareness initiatives we provide to the prostate cancer community free of charge. **To donate, please [CLICK HERE](#)** or visit [www.ustoo.org](http://www.ustoo.org).

By way of closure to periodic updates on the previous temporary shortage Xofigo<sup>®</sup>, **Bayer has resumed production of Xofigo** (radium Ra 223 dichloride) for new patients as of Monday, November 17th.

Two students working on their Master's degree at the University of Wisconsin – Milwaukee are conducting a **research study to assess/improve patient representation** in federal pharmaceutical policy-making and align the needs of the FDA with the prostate cancer community. **To take the 10-minute survey [CLICK HERE](#)**. No prior knowledge about the FDA is required. Any questions about the study can be addressed to [fabubacy@uwm.edu](mailto:fabubacy@uwm.edu) or [djcard@uwm.edu](mailto:djcard@uwm.edu).

While doing your holiday shopping online, remember to participate in the **Amazon Smile program**. Simply designate Us TOO International as your charity of choice and **0.5 percent of the value of all purchases will be donated to Us TOO**. There's no limit to the amount Amazon Smile will donate. Help spread the word to shop and help Us TOO.

**My best to you and yours this holiday season!**



T. N. Kirk, President & CEO