



## SFA Spotlight - August 2016

**Welcome to our newsletter!** Please be on the lookout for this newsletter every month as a way to keep you more involved and engaged with information important to the SFA community.

Please be sure to include [sfainfo@curesarcoma.org](mailto:sfainfo@curesarcoma.org) in your address book. If you do not wish to receive this email on a monthly basis, please [contact us](#).



### Hope and Help

*This post was written by Bert E. Thomas IV, PhD, MBA, CEO of the Sarcoma Foundation of America.*

Hope and Help is my patient advocacy motto.

I believe that one can characterize patient advocacy efforts into two buckets: activities focused on Hope and activities focused on Help. Hope for finding a cure and Help with the patient journey. Historically patients had the smallest voice in terms of advocacy, but that is not the case anymore. The accomplishment of the patient advocacy community in raising the impact and importance of the patient voice is a testament to how a group of people speaking with one voice can change the world for the better. Patients, and those who advocate for them, are leading the charge to find both the Hope and the Help that they so desperately need in their patient journey.

[Read more...](#)

## Take Action: Childhood Cancer STAR Act

We need your help! Time is running out for Congress to take up **The Childhood Cancer Survivorship, Treatment, Access, and Research (STAR) Act**. The STAR Act would expand opportunities for childhood cancer research, improve efforts to identify and track childhood cancer incidences, enhance the quality of life for childhood cancer



Childhood Cancer  
**STAR ACT**  
Survivorship Treatment Access and Research  
H.R. 3361 • 01/03

survivors, and ensure publicly accessible expanded access policies that provide hope for patients who have run out of options.

[Read more...](#)

---

## Denver City Council President Albus Brooks to Serve as Chair for the Inaugural Race to Cure Sarcoma Denver



Sarcoma survivor and Denver City Council President Albus Brooks will serve as the Chairperson for the inaugural Race to Cure Sarcoma Denver. The charity 5K run/walk will benefit the Sarcoma Foundation of America and the University of Colorado Cancer Center.

Brooks was diagnosed in July with Chondrosarcoma, a subtype of sarcoma. Sarcoma is a rare cancer of bone and soft tissue. It is rather rare in adults, comprising only 1 percent of all adult cancers, but accounts for 15 percent of childhood cancers. At any one time, 50,000 patients and their families are struggling with sarcoma. Every year, nearly 15,000 new cases are diagnosed and about 6,000 people die from the disease.

A 15-pound tumor was removed from Brooks during an eight hour surgery performed at the University of Colorado Anschutz Medical Campus. Brooks has praised the remarkable care that he received from his team of doctors, including Victor Villalobos, MD, PhD, a sarcoma specialist. Thanks to his treatment and the expertise of his physicians, Brooks is now cancer-free.

[Read more...](#)



**Denver Race to Cure Sarcoma**

September 17, 2016

Cherry Creek Dam Road in Greenwood Village

<http://support.curesarcoma.org/denver>

---

## 5th Annual Car Show for a Cure



Thank you to everyone who made the 5th Annual Car Show for a Cure a great success! This annual event, held in Sewell, NJ, honors the life of Derek Schnapp and raises money for the Sarcoma Foundation of America.

---

## New Patient Resource: You and Sarcoma

The Sarcoma Foundation of America, like many other sarcoma organizations, provides information about sarcomas, subtypes, and treatments on our website. This information is often in a text format which is great for some patients but not all. The SFA believes it is important to keep different learning styles in mind and has undertaken an effort, in collaboration with Mechanisms in Motion, to provide a new and unique learning channel for patients who are more interested in learning about their disease through animations and videos. We believe this is a major breakthrough for the sarcoma community and are proud to be providing this new learning opportunity to anyone interested in learning more about sarcoma.



The website for this new animated learning tool is at [youandsarcoma.com](http://youandsarcoma.com). The website is in pilot mode with two animations currently available. We are fundraising to expand the website with additional animations. This is where all of our members can be of great help.

The SFA would appreciate any and all feedback on the pilot site. Do you find the videos helpful? What other subjects would you like to see covered? Is there other feedback you would like to provide? This feedback can be shared with the SFA at [sfainfo@curesarcoma.org](mailto:sfainfo@curesarcoma.org).

We hope that the sarcoma community will find this to be a worthwhile endeavor and make the patient journey a little easier to manage.

---

## Upcoming Events

Check our [Upcoming Events section](#) on our website frequently for more ways to get involved.

Learn more about events like [Celebrating the Life of Steve Byrne](#), to be held on September 10, 2016, the [3rd Annual STL Cure Sarcoma 6K Run/Walk](#), to be held on October 9, 2016, the [Race to Cure Sarcoma Chicago](#), to be held on October 29, 2016, and the [Race to Cure Sarcoma Philadelphia](#), to be held on October 30, 2016.

**Make a Difference  
GET INVOLVED**



For a complete list of upcoming Patient Education Conferences, visit <http://www.curesarcoma.org/education/sarcoma-education-conferences/>.

Interested in getting involved? [Please let us know.](#)



Sarcoma Foundation of America | 9899 Main Street, Suite 204, Damascus, MD 20872  
301-253-8687 | [info@curesarcoma.org](mailto:info@curesarcoma.org) | [www.curesarcoma.org](http://www.curesarcoma.org)

STAY CONNECTED:

