

# Top Accomplishments of 2013

Significant steps we took this year thanks to your support to accelerate the development of a cure and to serve the needs of the chordoma community.

## Accelerating the Search for a Cure

### Uniting the Global Chordoma Research Field

We brought together more than 100 physicians and scientists from nine countries, including representatives from six pharmaceutical and biotech companies, for the Fourth International Chordoma Research Workshop to share the latest discoveries and form new collaborations. Highlights from the 28 presentations included:

- Several drugs were found to shrink chordoma tumors in mice.
- Important new chordoma cell lines, mouse models, and zebrafish models were developed and will be made available through Chordoma Foundation repositories.
- The first clinical practice guidelines for the treatment of chordoma were published, achieving a goal set at the first research workshop.

### Jumpstarting New Research

We awarded seed grants to four researchers to start promising new projects:

- Chetan Bettegowda, MD, PhD – **Johns Hopkins University**  
*Development of a personalized diagnostic test for individuals with chordoma.*
- Gregory Cote, MD, PhD – **Massachusetts General Hospital**  
*A translational study of epigenetic-based therapy in chordoma.*
- Adrienne Flanagan, MD, PhD – **University College London**  
in collaboration with **The Jackson Laboratory** (Bar Harbor, ME)  
*A genetically engineered mouse model of chordoma precursor tumors.*
- Andreas Fritz, PhD – **Emory University**  
*Developing a zebrafish chordoma model for high-throughput drug screening.*

This year we received a record 37 seed grant applications - more than twice as many than any previous year - reflecting a growing interest in chordoma research and a growing demand for research funding.

### Testing Promising Treatments

We expanded our ongoing Drug Screening Project at **Johns Hopkins University** to test 10 more FDA-approved drugs in two additional mouse models. Initial results from this project were published in *Cancer Biology & Therapy* in May and in *PLoS ONE* in November, providing the first solid laboratory rationale for clinical trials of already-approved drugs.

### Uncovering the Causes of Chordoma

We broadened our search for the genetic underpinnings of chordoma by funding the next phase of the Chordoma Genome Project at the **Wellcome Trust Sanger Institute** (Cambridge, England). Previously, this project revealed that the gene brachyury is altered in 97% of chordoma patients, but does not by itself cause chordoma. Now researchers are sequencing the entire genome of chordoma tumors to reveal all of the genetic changes that may work with brachyury to cause chordoma.



Dr. Garry Gallia of Johns Hopkins University and Dr. Menghang Xia of the NIH Chemical Genomics Center receive the Foundation's "uncommon collaboration" award from Board Chair Heather Lee for their their work to repurpose approved drugs to treat chordoma.



## Serving the Chordoma Community



Survivors Irith Abada and Kathy Milczarski.

### Facilitating Clinical Trial Participation

We kept patients informed about the latest clinical trial opportunities and **prompted researchers at the National Cancer Institute to include chordoma patients in the first-ever clinical trial of a therapy targeting brachyury** – a vaccine that stimulates the immune system to attack tumor cells that express brachyury.

### Providing Helpful Resources

We provided information and support to chordoma patients and family members across the world.

- Fulfilled over 150 requests for information, physician referrals and peer support.
- Disseminated patient educational materials to over 100 hospitals and clinics.
- Served an average of 11,000 monthly website visitors worldwide.

### Uniting Patients and Families

We brought together over 70 patients, family members, and friends in Boston at our Fourth Chordoma Community Conference to learn, connect and join forces to help advance the search for a cure. Sessions included:

- A question and answer forum with six expert physicians.
- Research updates presented by leading chordoma scientists.
- Information on nutrition and cancer, navigating the healthcare system, parenting with chordoma, “scanxiety”, the skill of happiness, and more.

### Partnering with the Chordoma Community

Embracing our commitment to be a partner and a resource to all who face chordoma, our Board of Directors formed an *Education and Outreach Committee* comprised of patients and family members to focus on how the Foundation can best serve the entire chordoma community. The committee’s charge is to advise the board about the needs of our community, and to develop plans for enhancing the Foundation’s programs to meet those needs.



Executive Director, Josh Sommer, with fellow survivor, John Nelson, and Education & Outreach Committee members Sharon Berlan and Hans Keulen.

Thank you for helping us make this progress possible. To stay up to date on our accomplishments, visit [www.chordoma.org/latest-updates/](http://www.chordoma.org/latest-updates/) or join us on Facebook at [www.facebook.com/chordomafoundation](https://www.facebook.com/chordomafoundation).

