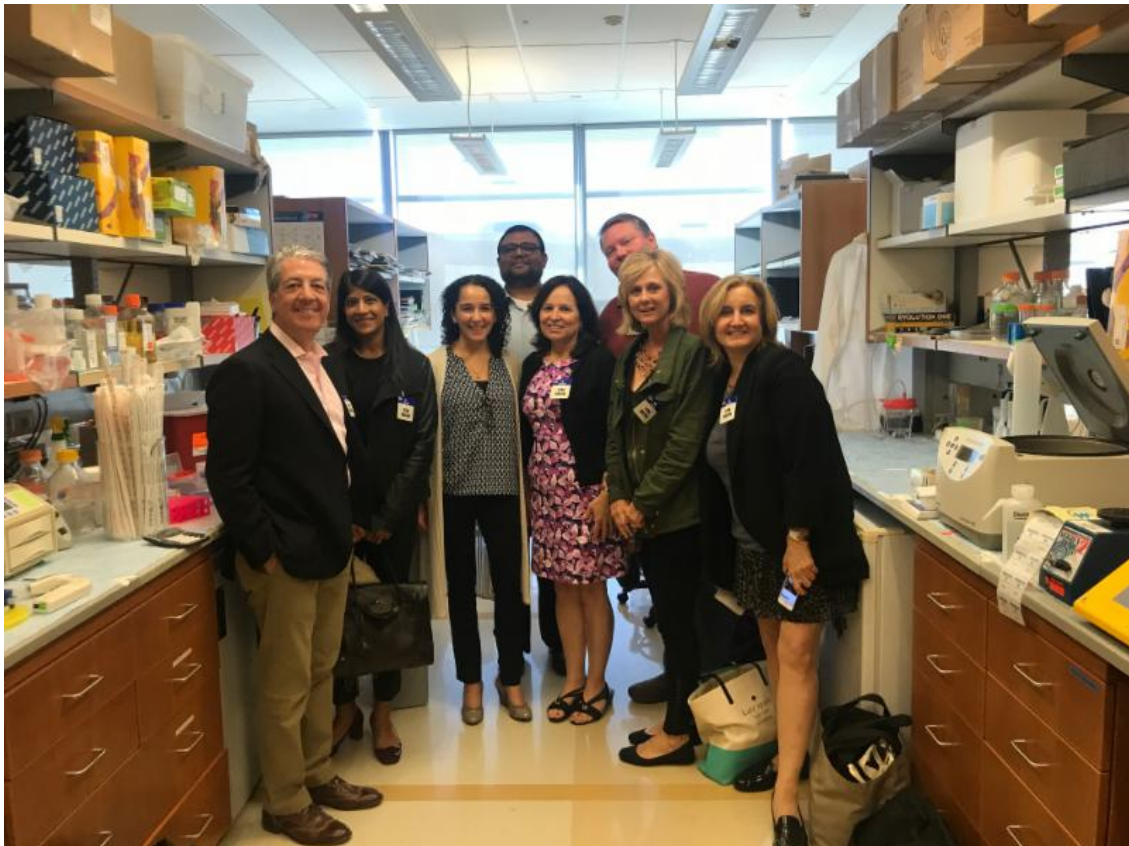


# BandWith

## Welcome to the Autumn 2017 Edition of BandWith!

In order to bring you the latest information about the clinical trials Band of Parents is funding, our Board of Directors hit the road! We recently visited the top neuroblastoma researchers in both Los Angeles and Philadelphia to hear firsthand how our grants are helping develop more effective, targeted treatments for our children.

Read on for highlights....



*Board of Directors with Dr. Yael Mosse, CHOP*

## NEW TRIALS

## Phase 1 Study of 131-1 mIBG, Nivolumab and ch14.18/CHO in relapsed/refractory neuroblastoma (MINIVAN)

Band of Parents has partnered with several like-minded nonprofit charities in funding a new trial of combination immunotherapy with targeted radiotherapy in children with neuroblastoma. Since more than 50% of children with high-risk neuroblastoma relapse after standard treatment, the hope is that this new regimen, if effective, would be integrated into frontline therapy in clinic. Researchers expect patients to tolerate the new combination therapy well enough that it could be delivered mostly on an outpatient basis. Thirty-six patients at four hospitals in the U.K., U.S., and Germany will be enrolled in the trial – the first-ever such combination therapy. *(University Hospital, Southampton, UK, University of Wisconsin, University Medicine, Greifswald, Germany, University Hospital, London; Drs. Juliet Gray, Paul Sondel, Holger Lode, Mark Gaze)*

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## OTHER TRIAL HIGHLIGHTS

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### Next Generation Personalized Neuroblastoma Therapy for Neuroblastoma (NEPENTHE), Children’s Hospital of Philadelphia

The Board of Directors received an on-site update from Dr. John S. Maris and Dr. Yael P. Mosse of the Children’s Hospital of Philadelphia (CHOP) on this ambitious Phase 1 study of innovative combination drug therapies for improving high-risk neuroblastoma survival. The trial matches genomic aberrations in neuroblastoma cells at the time of relapse to special combinations of molecularly targeted agents that have shown success in preclinical models. The team biopsies tumors in eligible patients with relapsed or primary refractory neuroblastoma. Tumor DNA and RNA are processed to identify protocol-specified biomarkers for targeted therapy. Twenty-four patients have been enrolled in the trial since August 2016. After the medical briefing, the board toured CHOP’s neuroblastoma laboratory, and the state-of-the-art Buerger Center for outpatient care. *(CHOP, Drs. John Maris and Yael Mosse)*

### New Approaches to Neuroblastoma Therapy Consortium, (NANT), Children’s Hospital of Los Angeles



Band of Parents Chairman Mark Winthrop and I were briefed by the NANT team at CHLA – which is the operations center for this wide-ranging trial that includes 18 children’s cancer centers across North America, Europe and Australia. As we reported in our last BandWith newsletter, we are co-funding a NANT trial of the promising lung cancer drug Lorlatinib, for use in children with ALK-driven neuroblastoma. The first patient has since been enrolled in this breakthrough trial. *(CHLA, Drs. Araz Marachelian, Robert C. Seeger, Shahab Asgharzadeh)*

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## UPCOMING EVENTS

Band of Parents is preparing for its annual families’ meeting with Dr. Nai-Kong Cheung and the Memorial Sloan Kettering Neuroblastoma Team in January, 2018. The event is a unique opportunity for Band of Parents members to hear updates on MSKCC’s latest trials, and to ask questions directly of the research team. There will also be a live online link for Band members to watch remotely, and text or email questions.

More details, including the exact date, to come soon!

## Save these Dates!

**Play Like a Pro** Charity Hockey Game in Honor of Talia Castellano - Feb. 9, 2018  
The 7<sup>th</sup> Annual Evening of Hope – April 25, 2018

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## PAST EVENTS

### COCKTAILS FOR A CURE

7/24/17

PhD Lounge, DREAM Downtown, NYC

On July 24<sup>th</sup>, Band of Parents raised more than \$52,000 at its 5<sup>th</sup> annual *Cocktails for a Cure* at the PhD rooftop lounge. The over-capacity crowd enjoyed Manhattan skyline views at our signature next-gen charity event.

Our gratitude to the management and staff of the PhD for helping to make this our most successful “Cocktails!”



### PUT CANCER IN THE PENALTY BOX

9/17/17

The Ice Hutch, Mt. Vernon NY

Youth surge for charity! New Rochelle teens Ethan Cohen and Josh Lebowitz helped raise over \$9,000 for Band of Parents at the second annual family skating charity event marking Childhood Cancer Awareness Month. Ethan's mom, Jill Ostrager-Cohen is the president of Band of Parents and her son Andrew, 10, is a two-time cancer survivor who was diagnosed with stage 4 neuroblastoma in 2010. In 2012, Andrew received the vaccine for high-risk neuroblastoma that Band of Parents helped fund. All proceeds from the fundraiser will be donated directly to Memorial Sloan Kettering Cancer Center to support childhood cancer research.



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## How to Help....

Want to raise money for Band of Parents, but don't know where to start? Go to [www.bandofparents.org](http://www.bandofparents.org) and see our "How to Help" section for the many ways to get involved with our mission.

Or contact me with any ideas or questions on how to help The Band. Thank you for supporting our research to save more children's lives!

With hope,

***Ronni Berke***

Executive Director

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