



## Pediatric Cancer Nanocourse

### Curriculum

August 20-24, 2018

cc-TDI laboratory, 12655 SW Beaverdam RD W, Beaverton OR 97005

Registration: <https://cc-tdi.kindful.com/register/2018-pediatric-cancer-nanocourse>

### Goals:

The goal of the Pediatric Cancer Nanocourse is to train members of the public to be informed liaisons between childhood cancer researchers and the community. Features of the course will include:

- a didactic overview of childhood cancer treatment, biology, pathology, and clinical trials
- an introduction to the scientific research process: how research works, what barriers exist, and how to overcome challenges and make progress on rare childhood cancers
- lectures on Epithelioid Sarcoma (EPS), Rhabdomyosarcoma (RMS), and Hepatoblastoma (HB)
- daily mentorship and hands-on opportunities to shadow our research scientists in the laboratory
- a self-selected group research project, with the opportunity to collaborate with fellow participants
- the opportunity to build a network of informed and empowered advocates who can drive the cure of rare cancers

Previous course members have had their findings published in [peer-reviewed scientific literature](#). There is no cost to attend the course (the \$100 registration fee is refunded when you arrive), but participants are required to cover their own travel, lodging, and meals. Participants are expected to attend the entire Nanocourse period. Attendance is limited, so please register early to secure your participation.

### 2018 Participants:

#### Hepatoblastoma Team:

Christina Stiverson

Cody Stiverson

Suzanne Kristopeit

Lisa Howard

Jessica & John Hester

Josh Griffin (♂)

Nicole Griffin (♂)

Beth Norton

Kim Webb

Lorna Day

Denny & Lennie Woods

#### Rhabdomyosarcoma Team:

Karen Caywood

Calleigh Germer

Scott Chaverri

Emily Sullivan

Cassie Santhuff

Matt Santhuff

Annie Horner

Elaine Horner

#### undisclosed:

Priya Ganesh

Nihar Koppolu

Sri Suresh Kumar

Bridget Price

#### Epithelioid Sarcoma Team:

Jill Cook

Cory or Tawni Norton

### HB Confirmed Lecturers:

Dr. Stefano Cairo (Xentech Inc), Biology of HB

Dr. James Geller (Cincinnati Children's Hospital), clinical trials for HB

Dr. Marcus Muench (UCSF), human liver development

Dr. Sanjeev Vasudevan (Baylor College of Medicine), surgical approaches to HD  
Dr. Rebecka Meyers (University of Utah), international hepatoblastoma collaborations

**Eps/RMS Confirmed Lecturers:**

Dr. Sheri Spunt (Stanford University), pediatric EPS/RMS clinical trials  
Matthew McBride (lab of Cigall Kadoch, Harvard), SWI/SNF complex in EPS  
Dr. Robin Jones (The Royal Marsden), adolescent & adult EPS/RMS clinical trials  
Dr. Torsten Nielsen (Univ of British Columbia), pathology & biology of EPS & RMS  
Dr. Heide Ford (Univ of Colorado), Six-Eya in RMS  
Dr. Deneen Wellik (Univ of Michigan), Wnt signaling (~HB, RMS)  
Dr. Charles Keller (cc-TDI), new agents to treat EPS/RMS

**Other Invited Lecturers:**

Deneen Wellik (Univ of Michigan), Wnt signaling  
Melanie Vincent (Univ of Colorado), Medulloblastoma  
Molly Lindquist (Consano.org), crowdfunding for biomedical research  
Ganapati Srinivasa (OmicsAutomation; Intel Collaborative Cancer Cloud, genomics  
Tommy Pham (Nike), industry partnerships

WiFi : *ask on arrival*  
Live Feed (selected): [click here](#)

**Itinerary and Curriculum (2 tracks):**

Mon Aug 20	Epithelioid Sarcoma/RMS	Hepatoblastoma
8:30 am	Welcome & Introductions; Lab Tour	same
9:00 am	Overview from an Academic & Pharma perspective <i>charles keller</i> <ul style="list-style-type: none"><li>- childhood cancer treatment</li><li>- clinical trials</li><li>- basic science research</li><li>- How to Cure Cancer from a Grassroots perspective: The Josh Sommer paradigm</li><li>- vocabulary</li></ul>	same
9:45 am	Project Introduction & Team Designation <i>andy woods</i> (Project Lead/Writer, Sub-project Leads) The goal of each project above is a roadmap manuscript for journal submission	same
10:00 am	EPS Overview <i>robin jones</i> <ul style="list-style-type: none"><li>- Genetic Landscape – now!</li><li>- Registry, biobank and info Website!</li><li>- more pediatric cultures, PDX models</li><li>- two-drug combinations for a complex disease</li><li>- concierge level care for relapse, starting at diagnosis</li><li>- current EPS research</li></ul>	

	- current EPS trials	
11:00 am	same	<b>HB overview <i>jim geller</i></b> <ul style="list-style-type: none"> <li>- metastatic &amp; relapsed HB management</li> <li>- registry wth DNA, RNA: researcher only or public?</li> <li>Biobank – central, or confederated?</li> <li>- Drug Development – faster; science-informed</li> <li>- Immunotherapy?</li> <li>- science of metastasis?</li> <li>- developmental biology of HB?</li> </ul>
12:00 pm	Lunch (pizza or sandwiches)	<b>Lunch and PitchFest:</b> the patient-owned, for-profit approach to an HB Registry <i>charles keller</i>
1:00 pm	<b>RMS Overview <i>sheri spunt</i></b>	<ul style="list-style-type: none"> <li>- topics to be taken from participants prior to course</li> <li>- metastasis</li> <li>- maintenance treatments</li> <li>- relapse treatments</li> <li>- alternative therapies (is there data?)</li> </ul>
2:00 pm	Project Work Time *	same
3:00 pm	<b>robotic drug screen:</b> stage 1 of 2 with <i>noah berlow</i> and <i>dina kats</i>	same
4:00 pm	<b>Reception with Nathan and Renee!</b>	
6:00 pm	<b>Group dinners with speakers</b> (locations TBA)	same

\* at various times, each person will rotate into the laboratory to shadow our scientists

Tue Aug 21	Epithelioid Sarcoma/RMS	Hepatoblastoma
8:00 am	EpS and RMS at the firsthand level <i>torsten nielsen</i>	same
9:00 am		<b>HB Genetics &amp; Models <i>stefano cairo</i></b>
10:00 am		<b>liver stem cell biology <i>marcus muench</i></b>
11:00 pm		open
12:00 pm	<b>LUNCH with SCIENCE: the SWI/SNF complex</b> <i>matthew mcbride</i>	
1:00 pm		<b>HB Surgery sparing vessels; vascular invasion research</b> <i>sanjeev vasudevan</i>
2:00 pm		<b>HB global collaboration <i>rebecka meyers</i></b>
3:00 pm	<b>Personalized Therapy <i>charles keller</i></b>	same
4:00 pm	Project Work Time *	same
5:00 pm		

Wed Aug 22	Epithelioid Sarcoma/RMS	Hepatoblastoma
8:00 am	Project Work Time *	same
9:00 am	Talk TBA Speaker TBA	
10:00 am		Bio-informatics Jam Session! with <i>Cora Ricker</i>
11:00 pm	Grass Roots Patient-Centered Research <i>molly lindquist</i>	same
12:00 pm	Lunch on your own	
1:00 pm	Volasertib for HB, and other egg issues <i>dina and samuel</i>	same
2:00 pm	Genomic Decisions – All in a Day <i>ganapati srinivasa</i>	same
3:00 pm	Project Work Time *	
5:00 pm	Dinner on your own	

Thu Aug 23	Epithelioid Sarcoma/RMS	Hepatoblastoma
8:00 am	same	Wnt signaling <i>deneen wellik</i>
9:00 am	Partnering with industry Tommy Pham	same
10:00 am	same	how I became a full time scientist for my daughter's cancer <i>andy woods</i>
11:00 pm	same	Egg-static about preclinical research <i>samuel rasmussen</i>
12:00 pm	Lunch and Learn: Targeting Eya2 in c-Myc driven Group3 Medulloblastoma <i>melanie vincent</i>	
1:30 pm	same	robotic drug screen: stage 2 of 2 <i>dina kats</i> and <i>noah berlow</i>
2:00 pm	Six-Eya signaling in RMS <i>heide ford</i>	
3:00 pm	Project Work Time *	

Fri Aug 24	Epithelioid Sarcoma/RMS	Hepatoblastoma
8:00 am	Project Work Time *	same
9:00 am	Project Finalization *	same
12:00 pm	Group Lunch (location TBA)	same
1:30 pm	Presentation of Completed Projects (manuscript submission?)	same
3:30 pm	Feedback Session	
5:00 pm	Nanocourse Conclusion	

## **Selected Pre-Reading & Media (required):**

Epithelioid Sarcoma Roadmap: <https://www.frontiersin.org/articles/10.3389/fonc.2015.00186/full>, or  
Hepatoblastoma Roadmap: <https://www.frontiersin.org/articles/10.3389/fped.2016.00022/full>

## **Selected Pre-Reading & Media (not required):**

I have mainly one video to suggest (Josh Sommer on his personal cancer journey and creating the Chordoma Foundation), an article, and a few short books. All of these are optional, but **the video of Josh Sommer is the highest potential value.** One of the books comes as a Hollywood movie.

The video of Josh Sommer: <http://pcb-ohsu.blogspot.com/2011/04/college-student-dedicated-to-curing-his.html>

The article: *Understanding Academic Medical Centers: Simone's Maxims.* Joseph V. Simone. *Clinical Cancer Research.* Vol. 5, 2281–2285, September 1999 (available at <http://clincancerres.aacrjournals.org/content/5/9/2281.long>)

This article is written by one of the first oncologists to try giving more than one chemotherapy drug at the same time, in this instance for childhood leukemia. He is the 'grandfather' of pediatric oncology and very much active to this day.

A book that became a movie: *The Cure: How a Father Raised \$100 Million--and Bucked the Medical Establishment--in a Quest to Save His Children.* ISBN-10: 006073440X

A painful but heartening book on just how far a parent can go to create a cure for their child. Its movie version, *Extraordinary Measures*, with Brendan Frasier and Harrison Ford:

<http://www.imdb.com/title/tt1244659/> (we could play this in the background during a project work session)

Other books:

*One Tough Mother*

A story of how a mom in an impossible situation built a billion dollar company. To some extent, curing cancer could take this kind of small business approach from the community.

ISBN-13: 978-1558689084

*Great by Choice: Uncertainty, Chaos, and Luck--Why Some Thrive Despite Them All*

ISBN-13: 978-0062120991

If you do reading about business strategies, you'll love this. if not, then most of what you need is in the first 2 chapters. The message is that in a downturned economy, stick to your mission and made careful decisions that are mindful of the most recent technology (or research).

*A Life Decoded*

ISBN-10: 0670063584

Sequencing the genome would take 15 years and 3 billion dollars... or does it take \$300 million and only 9 months? This is a real world story of going outside of the box.

*Leading for Growth: How Umpqua Bank Got Cool and Created a Culture of Greatness*

ISBN-13: 978-0787986070

What business are you *really* in? How can you empower people around you to achieve incredible things? Ray Davis speaks to this in the context of a bank, but it is anything but an ordinary story.

## **Attendee Suggestions:**

Global Genes overview of patient advocacy in drug discovery: <https://globalgenes.org/toolkits/from-molecules-to-medicines-how-patients-can-share-their-voices-throughout-the-drug-development-process/introduction/>

## A Note to Participants:

Dear Participants, Thank you for registering for the 2018 Pediatric Cancer Nanocourse!

### Location of the Nanocourse

cc-TDI laboratory  
12655 SW Beaverdam RD W  
Beaverton OR 97005

### Hotel Accommodations (selected)

The closest (utilitarian):  
Comfort Inn & Suites Beaverton - Portland West  
13455 SW Tualatin Valley Hwy, Beaverton, OR 97005 Tel  
(503) 643-9100.

New, nearby, maybe open in August:  
Marriott TownePlace Suites  
3900 SW 114th Street Beaverton, Oregon 97005

A good value, and very peaceful:  
River's Edge Hotel & Spa, 455 SW Hamilton Ct,  
Portland, OR 97239, Tel: (503) 802-5800

Hotel Modera  
515 SW Clay St, Portland, OR 97201, Tel: (503) 484-1084

Park Lane Suites and Inn  
-Downtown  
-30 minutes to the lab by MAX Blue Line  
-15 minutes to the lab by car

Embassy Suites by Hilton Portland Washington Square  
-10 minutes to the lab by car  
-20 minutes to the lab by bus  
-40 minutes to downtown Portland

The grooviest, downtown; check on hotels.com:

**Air and Ground Travel** PDX is served by most major airlines.

The MAX light rail starts within a few feet of the PDX airport, goes to downtown and even the cc-TDI lab. See <https://tHorimet.org/max/>.

In detail, our lab is a short walk from the light rail blue line (Beaverton Central stop) ... from the airport Max stop, you take the red line eastbound (it only goes eastbound) and change at the Beaverton transit center to the blue line westbound. The very first stop is Beaverton Central. Our address for GPS walking directions is 12655 Sw Beaverdam Rd W, Beaverton, OR 97005 ... or just cross the street to the south, and you're here (our door is on the south side of our building).

**About Portland** Situated between the Columbia River Gorge and the Oregon Coast beaches, the greater Portland area is home to great restaurants and diverse cultural attractions and events. Our lab is 10 minutes east of Portland in the sister city, Beaverton, where Nike headquarters are.

Sincerely, Charles

**Charles Keller MD | Scientific Director**  
**Children's Cancer Therapy Development Institute**  
direct: (801) 232-8038 | [charles@cc-TDI.org](mailto:charles@cc-TDI.org) | <http://cc-TDI.org>