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**Pediatric Cancer Nanocourse**

**Curriculum**

**August 14 - 18, 2017**

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

**Registration (now closed):**

<https://cc-tdi.kindful.com/register/2017-pediatric-cancer-nanocourse>

**Goals:**

The goal of the Pediatric Cancer Nanocourse is to train members of the public to act as 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 Bloom Syndrome and ETMR, as well as leptomeningeal metastasis of CNS PNET tumors
* 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](http://www.ncbi.nlm.nih.gov/pubmed/24481909). There is no cost to attend the course, but participants are required to cover their own travel, lodging, and meals. **Attendance is limited, so please register early to secure your participation.**

***2017 Participants:***

*Bloom Syndrome Team:*

*11 attendees*

*ETMR Team:*

*4 attendees*

*Metastatic leptomeningeal PNET:*

*6 attendees*

*undeclared:*

*6 attendees*

Confirmed Lecturers:

Dr. Chris Cunniff (Weill Cornell), Bloom Syndrome and the BS Registry (Aug 13/14) [cmc9039@med.cornell.edu](mailto:cmc9039@med.cornell.edu)

Dr. Mark Osborn (Univ of Minnesota), Gene Therapy for Fanconi Anemia/BS (Aug 14/15) [osbor026@umn.edu](mailto:osbor026@umn.edu)

Dr. Nathan Ellis (Univ of Arizona), Questions in Bloom syndrome (Aug 15/16) [naellis@email.arizona.edu](mailto:naellis@email.arizona.edu)

Dr. Sharon Plon (Baylor), inherited cancer predisposition wellness programs (Aug 14) [splon@bcm.edu](mailto:splon@bcm.edu)

Dr. Erin Rudzinski (Seattle Childrens), Bloom Syndrome cancer pathology (Aug 15) [Erin.Rudzinski@seattlechildrens.org](mailto:Erin.Rudzinski@seattlechildrens.org)

Dr. Annie Huang (Sick Kids), ETMR Overview (Aug 15) [annie.huang@sickkids.ca](mailto:annie.huang@sickkids.ca)

Dr. Jonathan Hall (ETH Zurich), Lin28 inhibitors (Aug 15/16) [jonathan.hall@pharma.ethz.ch](mailto:jonathan.hall@pharma.ethz.ch)

Dr. Mollie Meffert (JHMI), Lin28 Biology (Aug 14) [mkm@jhmi.edu](mailto:mkm@jhmi.edu)

Dr. Marcel Kool, (German Cancer Research Center), ETMR Functional Genomics (Aug 13-16) [m.kool@Dkfz-Heidelberg.de](mailto:m.kool@Dkfz-Heidelberg.de)

Dr. Mariella Filbin (DFCI), Single-cell genomics in pediatric brain tumors (Aug14-15) [Mariella.Filbin@childrens.harvard.edu](mailto:Mariella.Filbin@childrens.harvard.edu)

Dr. Derek Hanson (Hackensack Univ Medical Center), ETMR trials (Aug 14-15) [Derek.Hanson@hackensackmeridian.org](mailto:Derek.Hanson@hackensackmeridian.org)

Dr. Bonnie Cole (Seattle Childrens), ETMR tumor pathology (Aug 15) [Bonnie.Cole2@seattlechildrens.org](mailto:Bonnie.Cole2@seattlechildrens.org)

Molly Lindquist (Consano.org), crowdfunding for biomedical research (Aug 16) [molly@consano.org](mailto:molly@consano.org)

Ganapati Srinivasa (OmicsAutomation; Intel Collaborative Cancer Cloud, genomics (Aug 16) [gans@omicsautomation.com](mailto:gans@omicsautomation.com)

Tommy Pham (Nike), industry partnerships (Aug 17) [tommy@cc-tdi.org](mailto:tommy@cc-tdi.org)

Pending Invitees:

Bloom Syndrome speaker on immunology/gene correction

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

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| Mon Aug 14 | Bloom Syndrome | ETMR |
| 8:30 am | **Welcome** & Introductions; Lab Tour | same |
| 9:00 am | **Overview** from an Academic & Pharma perspective   * childhood cancer treatment * clinical trials * basic science research * How to Cure Cancer from a Grassroots perspective: The Josh Sommer paradigm | same |
| 9:45 am | **Project Introduction & Team Designation** (Project Lead/Writer, Sub-project Leads)  The goal of each project above is [a roadmap manuscript in Frontiers](http://journal.frontiersin.org/researchtopic/5871/pioneering-for-the-orphan-cancer-domain-community-facing-roadmaps-for-the-most-rare-pediatric-andor) | same |
| 10:00 am | **Bloom Syndrome Overview** Chris Cunniff  *Growth & Nutrition – when to intervene? Is growth hormone contraindicated?*  *Immune Dysfunction – what is it, what to do?*  *Diabetes – why, and are there prevention measures?*  *Cancer Surveillance – how? how often?*  *Cancer Prevention – is this feasible?*  *Relatives – what’s the cancer risk?*  *Cancer Treatment – surviving the first cancer while preventing a second?*  *Cures – exon skipping, gene editing and gene therapy?* |  |
| 10:55 am | same | **ETMR overview** deferred to Tue 10am |
| 12:00 pm | **Lunch** (pizza or sandwiches) and **Gene Therapy for Fanconi’s Anemia** Mark Osborn | same |
| 1:00 pm |  | **Lin28 Biology** Mollie Meffert |
| 2:00 pm | Project Work Time \* | same |
| 3:00 pm | **robotic drug screen:** stage 1 of 2 *with Noah Berlow* | same |
| 4:00 pm | **Inherited cancer predisposition wellness programs** Sharon Plon |  |
| 6:00 pm | **Group dinners with speakers** (locations TBA) | same |

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

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| Tue Aug 15 | Bloom Syndrome | ETMR |
| 8:00 am |  | **Leptomeningeal PNETs** Morgann Turkot  *This is not a formal roadmap project, unless a breakout team wishes to form.* |
| 9:00 am |  | **ETMR Functional Genomics** Marcel Kool |
| 10:00 am |  | **ETMR Overview** Annie Huang  *Lin28 drives the cancer. Therapeutics exist and continue to be developed. Few preclinical resources (cell lines o*r mouse models) have been developed. What is the path forward? |
| 11:00 pm |  | **Lin28 inhibitors** Jonathan Hall |
| 12:00 pm | Lunch on your own |  |
| 1:00 pm |  | **Single-cell Genomics in pediatric brain tumors** Mariella Filbin |
| 2:00 pm |  | **ETMR Clinical Trials**  Derek Hanson |
| 3:00 pm | **Cancers at the first-hand cellular level**: Erin Rudzinski speaking on **Bloom Syndrome** cancers; Bonnie Cole speaking on **ETMR** | same |
| 4:00 pm | Project Work Time \* | same |
| 5:00 pm |  |  |

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| Wed Aug 16 | Bloom Syndrome | ETMR |
| 8:00 am | Project Work Time \* | same |
| 9:00 am | **Immunology in Bloom Syndrome** ~~Khashayarsha Khazaie~~ TBD |  |
| 10:00 am |  | **“The ETMR pilot project, hands on for you”**  Noah Berlow |
| 11:00 pm | **Grass Roots Patient-Centered Research** Molly Lindquist | same |
| 12:00 pm | Lunch on your own |  |
| 1:00 pm | **Genomic Decisions – All in a Day** Ganapati Srinivasa | same |
| 2:00 pm | **Questions in Bloom syndrome** Nathan Ellis | same |
| 3:00 pm | Project Work Time \* |  |
| 5:00 pm |  |  |

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| Thu Aug 17 | Bloom Syndrome | ETMR |
| 8:00 am | Project Work Time \* | same |
| 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** Andy Woods |
| 11:00 pm | same | **Egg-static about preclinical research**  Samuel Rasmussen |
| 12:00 pm | Lunch on your own |  |
| 1:30 pm | same | **robotic drug screen:** stage 2 of 2 *with Noah Berlow* |
| 2:00 pm | Project Work Time \* |  |
| 5:00 pm |  |  |

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| Fri Aug 18 | Bloom Syndrome | ETMR |
| 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 (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 Mesures*, 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 I mentioned: <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 2017 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.

A good value, and very peaceful:

River's Edge Hotel & Spa, 455 SW Hamilton Ct,

Portland, OR 97239, Tel: (503) 802-5800

The grooviest, downtown; check on hotels.com:

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

**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 | http://cc-TDI.org