

PHYSICAL SCIENCES —
— in ONCOLOGY



CANCER
RESOURCE
CENTER

OF THE FINGER LAKES

Connecting Researchers and Patients: Practical First Steps

Bob Riter
Cornell University
Physical Sciences Oncology Center

Research Review Panels: Decisions to Fund Research



Realizations

- Consumers on the panels are afraid of scientists.
- Scientists on the panels are just as afraid of consumers.

Further Realizations

- Many doctoral students and postdocs in the basic sciences never meet patients affected by the disease they are studying
- Engaging with interested non-scientists should be part of their professional development

Moving Upstream

- We know it's good to connect researchers with the patient community
- Why not connect *researchers-in-training* with the patient community?

Objectives for students

- Training and experience in science communication
- Exposure to the human side of disease

Idea #1: Keep it Simple

- Connecting scientists and patients doesn't have to be complicated.
- It can begin with one interested patient.

Idea #2: Begin by listening

- Begin by organizing a session in which patients/survivors/family members can share their personal stories with researchers.

CANCER RESEARCH: THE PATIENT'S VOICE



Wednesday, Oct. 10, 5:15 – 6:30 pm
Vet School, Classroom 6

Learn about cancer from those who live with it on a daily basis. Patients, survivors and family members will share their experiences and answer questions from students. Everyone is welcome, and new graduate students interested in cancer research are especially encouraged to attend.

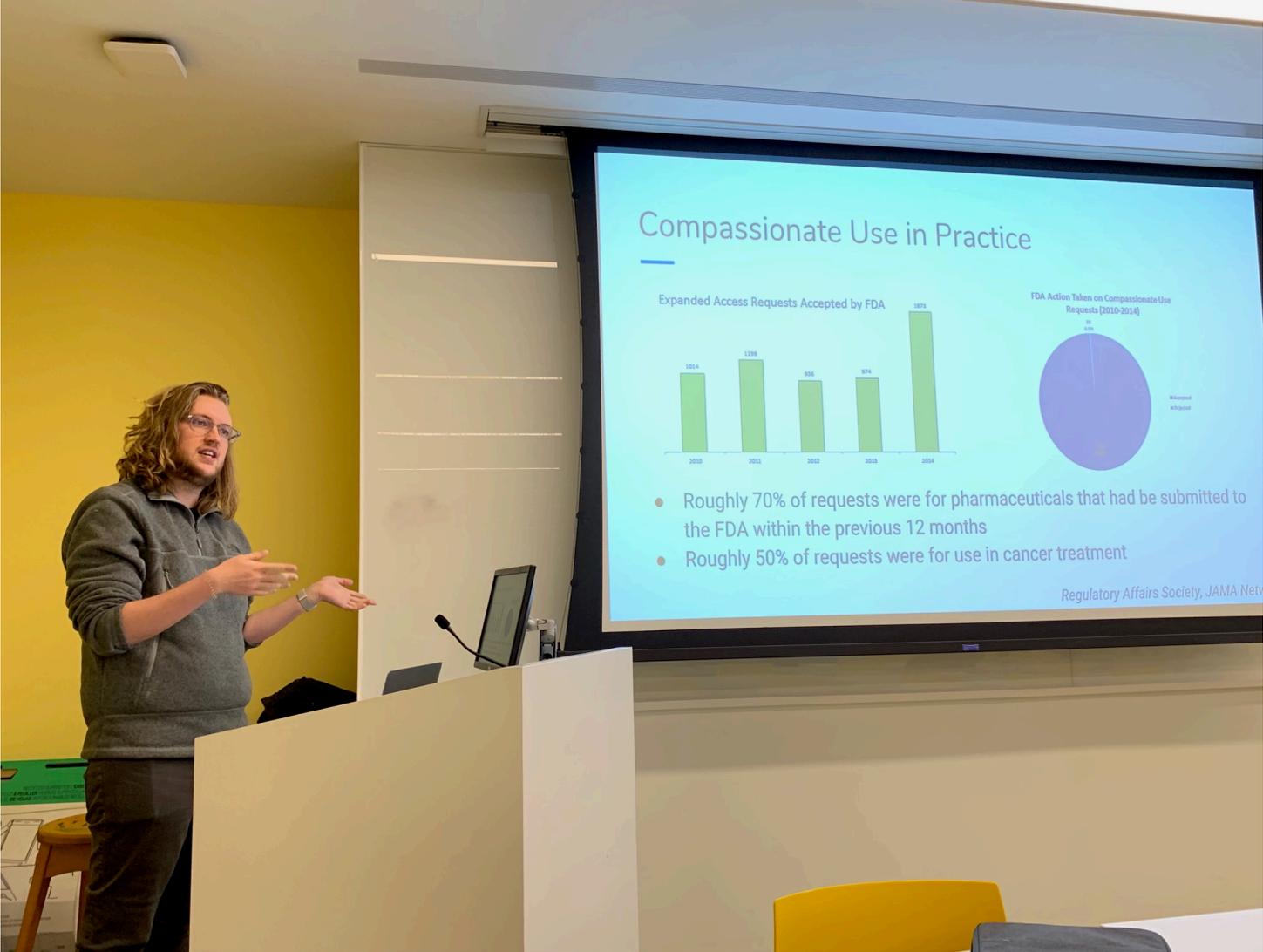
A program of the Cornell Cancer Partnership
Light refreshments will be served. Free parking at the Vet School (B Lot) after 5:00
For more information, contact Bob Riter at RNR45@cornell.edu





Idea #3: Ask the patients/survivors what they want to learn

- Ask the patients/survivors if they'd be interested in learning more about the science of their disease.
- Have doctoral students and postdocs make presentations on these broad topics on regular basis, e.g., once a month. (Do not have them present their own research – they'll get too technical).

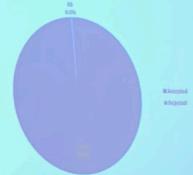


Compassionate Use in Practice

Expanded Access Requests Accepted by FDA



FDA Action Taken on Compassionate Use Requests (2010-2014)



- Roughly 70% of requests were for pharmaceuticals that had been submitted to the FDA within the previous 12 months
- Roughly 50% of requests were for use in cancer treatment

Regulatory Affairs Society, JAMA Netw

Special Instructions for Community Members

- Don't ask for medical advice. The students aren't physicians, and the physicians who do attend are not there for that purpose.
- Ask questions. Part of the rationale for the course is to give students practice in explaining science to the public.
- If you have a science background, remember that we'd rather learn about the science from the students and faculty.

Special Instructions for Community Members (cont.)

- Remember that the students are students. Be supportive and kind.
- Don't focus exclusively on your own illness.
- We encourage community members to share their own medical experiences throughout the semester, *but don't overshare*. These aren't medical students. They don't need to know every gory detail.
- Bring positive energy to the class.

Special Instructions for Students

- Be professional. Always follow-through with your commitments.
- Be engaged during the class. Don't go through your email or otherwise distract yourself and your neighbors.
- Know that it's ok to ask questions to community members. We want to share with you.
- Bring positive energy to the class.

Idea #4: Recruit for patients/survivors on campus

- Any large research university will have a sizeable population of patients and survivors on staff who are interested in learning more about their illness and in nurturing the next generation of researchers.
- Welcome family members as well. Their perspective is just as important.

Idea #5: Make it a big tent

- Many universities engaged in basic medical research don't make an effort to connect students from different academic disciplines.
- Hearing from patients cuts across disciplines and connects students who otherwise may not meet one another.
- Invite everyone.

Idea #6 Make it Fun - Speed Dating



Idea #7: Create a “People’s Choice” Award for Scientific Posters

- Organize poster sessions in which the students present their work – in lay language – to advocates. Have the advocates select prize winners in such categories as clearest explanation, most enthusiastic presenter, best visuals, etc.

The People's Choice Committee



Idea #8: Offer a Lay Abstract Contest

- Community members can review lay abstracts written by researchers-in-training and recognize those that are truly written for a lay audience.

Idea #9: Identify students for leadership roles

- Most students become involved in medical research because they are passionate.
- Consider giving one or two committed students a stipend and/or title to assist in coordinating the program.



Alexandra
McGregor



Peter DelNero

From patients to partners

When we started graduate school 5 years ago, we were determined to learn everything we could about cancer. We spent all our time in the lab developing an arsenal of experimental techniques. However, in our daily work with petri dishes and microscopes, we felt that something was missing. We learned all about tumor biology, but we knew very little about the human dimensions of cancer. Even though our research is far from the clinic, we believed that interacting with patients and survivors would improve our understanding of cancer and the quality of our science.

With permission from our advisers, we contacted the director of a local cancer center to find out whether he might be interested in working with us. He was enthusiastic about connecting scientists-in-training with the cancer community; in fact, he was already discussing this idea with another group at our university. Together, we started hosting monthly seminars where researchers and patients interact and learn from each other. Some months, a graduate student gives a lay-language presentation about an important aspect of cancer research. Other months, community members describe their experiences of living with cancer. We also organize informal activities that promote patient-researcher dialogue, such as lab tours, book clubs, and participation in cancer support groups. One lung cancer survivor even spent a summer conducting experiments with us. Our relationship with the cancer center has created a continuous stream of new opportunities.

The partnership with the patient community has deeply influenced our formation as scientists. Our conversations have revealed gaps in our knowledge, exposed biases and assumptions, and even opened new paths for inquiry. We have learned about the hidden costs of cancer and the day-to-day obstacles patients face with their work, health insurance, family life, and plans for the future. By speaking with cancer patients, we have also learned to exercise openness, empathy, and reflective listening. Over time, we have fostered special relationships with patients and family members, and many have become our closest friends. Occasionally, we come face-to-face with the devastating reality that current treatments are not good enough.

The patient-researcher partnership transformed our research from an intellectual exercise into a deeply personal



“The patient-researcher partnership transformed our research.”

evolved into a formal curriculum for public engagement in cancer research. This aspect of our work became a highlight of our graduate experience.

Through our partnership, we discovered that research is not the only way that scientists can make a positive difference in the fight against cancer. Outside the lab, we can nurture personal relationships with individual patients, survivors, and families. Researchers are well placed to disseminate information, dispel common misconceptions, and share the scientific process with the cancer community. Most importantly, we can be good, supportive listeners. As we pursue the next phase in our research careers, we know that our patient involvement will continue. For us, it has become an integral part of what it means to be a cancer scientist. ■

Peter DelNero and Alexandra McGregor are doctoral students at Cornell University. They gratefully acknowledge Bob Riter, Robert Weiss, and all the community members and students who have been involved in the partnership.

endeavor. It reminds us that people with cancer are not merely cells or molecular pathways. They are neighbors, colleagues, friends, and relatives. They are valued partners in the fight against cancer. As one of our colleagues explained, “I used to care about accomplishments and great publications, but now I simply want to generate data that will be most reliable and important for improving cancer therapy.”

Early in the process, we felt nervous about taking time and energy away from our lab work to develop this program. We felt we were “breaking the rules” for graduate student conduct. But we decided to ignore this nagging anxiety, and we gave ourselves permission to continue. With help from a team of faculty members, the partnership

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Idea #10 Create an Education Day for Community Members



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Cancer Research Education Day



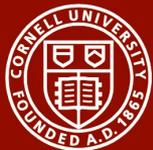
September 7, 2017
Weill Hall
Cornell University

Agenda

10:00	Welcome (Bob Riter)
10:00 – 10:30	Putting Cancer in Context: Understanding the Tumor Microenvironment (Garrett Beeghly)
10:30 – 11:00	How engineering contributes to our understanding of cancer (Pragya Shah and Jeremiah Hsia)
11:00 – 11:15	Break
11:15 – 11:45	From smoking to obesity: The new focus in cancer prevention (Prof. Claudia Fischbach)
11:45 – 12:15	Understanding cancer begins with understanding DNA (Prof. Robert Weiss)
12:15 – 12:30	Group photo and grab lunch
12:30 – 1:00	Ask the experts (and soon-to-be experts!)
1:00 – 1:30	Tumor heterogeneity: Tumors are more complicated than we thought (Elizabeth Moore)
1:30 – 2:00	CRISPR: We've heard the term, but what is it? (Marquita Winters)
2:00 – 2:30	Cancer Immunotherapy - The Double-Edged Sword (Kristel Yee Mon and James Cockey)
2:30 – 3:00	Precision Medicine in Cancer Care: The -omics age is here (Jon Villanueva)

Idea #11: Provide lay language talks before scientific presentations

- When a scientific lecture is scheduled on-campus, provide a lay-language talk, led by a doctoral student or postdoc, on the general topic for advocates and interested members of the public.



DISTINGUISHED LECTURE IN CANCER BIOLOGY

*Sponsored by the Sandra Atlas Bass Endowment for Cancer Research and
the Comparative Cancer Biology Program at the College of Veterinary Medicine*



Joan Massagué, PhD

Executive Director, GMTEC and
Director, Sloan Kettering Institute,
Memorial Sloan Kettering Cancer
Center

Origin, Latency and Outbreak of Metastatic Stem Cells

Tuesday, September 18th

4:00 pm - 5:00 pm

Schurman Hall, Lecture Hall 4/5 (S1-210/2)

Primer Talk @ 3 pm, Vet Research Tower, LH3

Student-led intro presentation on metastasis and cancer stem cells

Imma Fernandez, Weiss Lab

Matt Whitman, Fischbach Lab

*If you need special accommodations or would like more information,
please contact Jackie Creque (jackie.creque@cornell.edu)*



Primer Talk @ 3 pm, Vet Research Tower, LH3
Student-led intro presentation on metastasis and cancer stem cells
Imma Fernandez, Weiss Lab
Matt Whitman, Fischbach Lab

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Idea #12: Piggy-back onto other Community Events



Biden Cancer Community Summit in Ithaca

The Cancer Resource Center of the Finger Lakes and cancer researchers at Cornell University are participating in a local Biden Cancer Community Summit on Friday, September 21.

Three events are scheduled and are designed to connect scientists with individuals in the community affected by cancer. All events are free and open to the public.

8 – 9 am: Men’s Breakfast Club Discussion

Dr. Joe Druso and Dr. Elizabeth Moore will join the weekly Men’s Breakfast Club at the Royal Court Restaurant (529 S. Meadow St.). They will highlight the evolution of chemotherapy and cancer treatment in general. This is an informal discussion over breakfast. Women and men are welcome to participate.

11:15 am-12:15 pm “Cancer Immunotherapy”

The rapidly developing world of Cancer Immunotherapy is the topic of a presentation by Dr. Timothy Pierpont and Regan Stephenson at the Cancer Resource Center (612 West State St.)

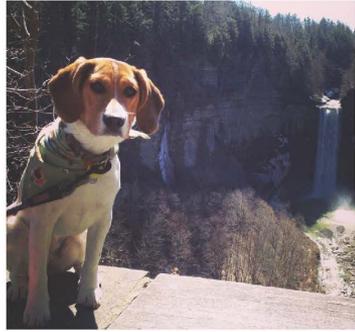
3:00 – 4:30 pm: “Ask a Cancer Scientist”

Cornell researchers Dr. Kelly Hume and Dr. Marc A. Antonyak will informally answer questions about cancer research at the Cancer Resource Center. (612 West State Street). Where has it been and where is it going? You’ll be surprised at the amount and variety of cancer research being done in Ithaca.

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Idea #13: Explore other community collaborations

**Cancer:
Simple Wisdom
from our Pets**



 **CANCER
RESOURCE
CENTER**
OF THE FINGER LAKES

 SPCA of Tompkins County
CELEBRATING 110 YEARS

INTEGRATIVE MEDICINE

Understanding Treatment Customs

IT'S HARD TO CHOOSE and comply with cancer treatments if you don't understand your diagnosis, your choices or your rights as a patient. But many who are new to the United States find themselves in exactly that position.

That's why the Cancer Resource Center of the Finger Lakes, in New York, took measures to clarify the basic customs surrounding U.S. cancer treatment and then collaborated with the Translator Interpreter Program of Cornell University to present those principles in a variety of languages. That information is available for free online at <http://tinyurl.com/j5wgxuh>.

The Resource Center sought input from cancer experts around the country in devis-

ing the list of principles. Included are the following ideas:

- › Doctors usually speak directly with the person who has cancer.
- › Doctors are honest with their patients. They will tell patients about the cancer.
- › Patients are encouraged to ask their doctor questions if they do not understand something or if they want more information.
- › Controlling pain and nausea is very important, and no one should suffer.
- › Medical information is kept confidential.

The program won a Town-Gown Award from Cornell.

The Translator-Interpreter Program at the Cornell Public Service Center trains Cornell students and staff who speak more than one language to serve as volunteer translators/interpreters for community agencies.



The Resource Center offers information, support, networking, wellness programs and financial advocacy.

"Our motto is that no one should face cancer alone," says Bob Riter, executive director of the Resource Center. "We work especially hard to support immigrants, who are more likely than anyone to feel isolated because of potential language and cultural barriers." — *BFI*



Idea #14 Talk about your interest in science

HOW DOES RESEARCH HAPPEN?

TWO CORNELL CANCER RESEARCHERS SHARE THEIR
EXPERIENCE WITH THE PRACTICAL SIDE
OF ACADEMIC RESEARCH

Robert Weiss, PhD
Professor of Molecular
Genetics, Department of
Biomedical Sciences

Associate Dean for
Research and Graduate
Education, College of
Veterinary Medicine



Claudia Fischbach, PhD
Professor, Nancy E. and Peter
C. Meinig School of Biomedical
Engineering

Director, Cornell Center on the
Physics of Cancer Metabolism

Wednesday, Nov. 7, 5:15 – 6:30 pm
Vet School, Classroom 6

Learn how scientists translate an idea into actual research. Funding, tenure, publishing, hiring a staff, and everything else you've wondered about! Everyone is welcome.

A program of the Cornell Cancer Partnership
Light refreshments will be served. Free parking at the Vet School (B Lot) after 5:00
For more information, contact Bob Riter at RNR45@cornell.edu



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Idea #15: Connect patients with other classes



Idea #16 Encourage Personal Connections



Acknowledgment



Robert Weiss, PhD

Professor of Molecular Genetics

Department of Biomedical Sciences

Associate Dean for Research and Graduate Education

College of Veterinary Medicine

Cornell University



Bob Riter

Cornell Physical Sciences Oncology Center

[http://blogs.cornell.edu/cancercommunitypartnership/
RNR45@cornell.edu](http://blogs.cornell.edu/cancercommunitypartnership/RNR45@cornell.edu)

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