

Connecting Cancer Patients and Cancer Researchers

A simple approach

Bob Riter

Cornell University Physical Sciences Oncology Center

Observations

- Connecting scientists and advocates doesn't have to be complicated.
 - Many doctoral students in the basic sciences who are doing cancer research have never met a person with cancer.
 - There's no single right way to do it.
 - Don't get hung up on defining what an advocate is or what their role should be.
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Idea #1: Reframe your thinking

- Don't ask: “How do I get an advocate?”
 - Do ask: “How can we connect cancer scientists with people in our community who have cancer?”
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Idea #2: Focus on researchers-in-training

- Doctoral students and postdocs often want to hear about the human side of cancer.
 - During their careers, they will interact with advocates on review panels and their relatives will ask for their advice on cancer-related issues.
 - Engaging with interested non-scientists should be part of their professional development.
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Idea #3: Begin by listening

- Begin by organizing a session in which patients/survivors/family members can share their personal stories with researchers.
 - It's better to have 5-8 individuals share their stories for a few minutes each as opposed to one speaker sharing a lengthier story. (Students should be exposed to a range of cancers and experiences).
 - Be sure to include patients with metastatic disease.
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Idea #4: Recruit for patients/survivors on campus

- Any large research university will have a sizeable population of cancer patients and survivors on staff who are interested in learning more about cancer and in nurturing the next generation of cancer researcher.
 - Welcome family members as well. Their perspective is just as important.
 - Make a request for speakers in the employee newsletter and/or listserv.
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COMMUNITY BASED CANCER RESEARCH PRESENTATIONS AND DISCUSSIONS

BIOMS 5665

Spring 2018

GUEST LECTURE: Ruth Collins “The lab to patient perspective”



CLINICAL INFORMATION:
Locally advanced cancer of the left breast. Status post
mastectomy chemotherapy for locally advanced cancer of the left
breast. Prophylactic right breast.
HISTOPATHOLOGIC DIAGNOSIS:
D. Frozen section diagnosis: Positive for carcinoma.

Instructors

Robert Weiss, PhD (rsw26);
Professor, Dept. of Biomedical
Sciences

Bob Ritter
(bobritter@gmail.com); patient
advocate

Alexandra McGregor
(alm358); graduate student

Aaron Chiou (aec267);
graduate student

Bruce Lewenstein, PhD
(b.lewenstein); Professor, Dept.
of Communication

Kristy Richards, PhD
(kristy.richards); Professor,
Dept. of Biomedical Sciences

Wednesday
FEBRUARY 7TH
5:15-6:30PM
LOCATION
Warren 101

*“People with cancer want
scientists involved in
cancer research to
understand that they are
more than cells or
molecular pathways. They
are people first!”*

Bob Ritter

Idea #5: Ask the patients/survivors what they want to learn

- After listening to presentations by the patients/survivors, ask them if they'd be interested in learning more about the science of cancer.
 - If so, which broad topics are of greatest interest? For example:
 - Immunotherapy
 - Metastasis
 - Tumor markers
 - Personalized medicine
 - 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).
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Fall Seminar Series

A Collaboration Between Cancer Researchers at Cornell University
and the Cancer Resource Center of the Finger Lakes

Patients and Family Members Share their Experiences with Students

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

This is the annual session in which we share our experiences with students, especially new graduate students at Cornell who are interested in cancer research. It's perhaps the most meaningful session of the year and has a lasting impact on the students.

How does Research Happen?

Wednesday, Nov. 7, 5:15 - 6:30 (Location TBA)

How does a cancer scientist take an idea and turn it into a project? How do you obtain funding? How do you set up a lab? What happens behind the scenes? Cornell Professors [Bob Weiss](#) and [Claudia Fischbach](#) will share their experiences and perspectives.

Lab Tours and Research Methods

Wednesday, Dec. 5, 5:15 - 6:30 (Location TBA)

We're arranging tours of some labs and a chance to learn about the concepts we hear about in many of our seminars. For example, what's a cell line? What's a mouse model? An organoid? (Watch for more details).

Everyone is welcome to subscribe to the Cancer Community Partnership listserv and receive notices of upcoming events and programs by sending a blank email to cancer-community-partnership-l-request@cornell.edu. Write "join" in the subject line and leave the rest of the message blank.

Idea #6: make it a big tent

- Many universities engaged in basic cancer research don't make an effort to connect students from different academic disciplines.
 - Hearing from cancer patients cuts across disciplines and connects students who otherwise may not meet one another.
 - Invite everyone.
 - Make it fun – bring in pizza, etc.
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Speed Dating



Idea #7: Advocates can help train scientists in presenting their work to lay audiences

- 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.
 - Have advocates review lay abstracts. Give prizes to the most understandable and to the most compelling.
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The People's Choice Committee





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.

For more information about the events, contact Bob Riter at RNR45@cornell.edu.



Idea #8: Identify students for leadership roles

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

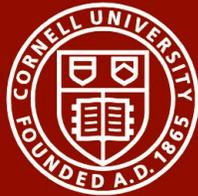
Peter DelNero and Alexandra McGregor are doctoral students at Cornell University. They gratefully acknowledge Bob Riter, Robert Weiss, and all the community members and students who have been involved in the partnership.

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

Idea #9: provide lay language primers before scientific presentations

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

Ima 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
Irma Fernandez, Weiss Lab
Matt Whitman, Fischbach Lab

The Cornell- Cancer Resource Center Collaboration in Ithaca



For more information:
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