

CANCER RESEARCH FUNDATION

The Mission of The Cancer Research Foundation Is To Help Find The Cures For Cancer Through Funding Laboratory and Clinical Research.

DNA. RNA. Genetic manipulation. Translational research. Gene splicing. Stem cells. Apoptosis. Signal transduction. Tumorigenesis. T cells. Oncogenes.

Cancer scientists come to the Cancer Research Foundation and ask us to fund their research projects, enterprises whose descriptions contain those words, along with other unfamiliar words. So, how do we find out just what they plan to do, what these molecular biologists and biochemists and geneticists and cell biologists are going to do in their laboratories?

We know that science is vital to sustain life, and that it is an ongoing process of discovery to unravel the secrets. We all want to help cure cancer. We are predisposed to want to support the Chicago academic scientists who ask for our help. And yet their science and project descriptions are complex.

“Most of the fundamental ideas of science are essentially simple, and may, as a rule, be expressed in a language comprehensible to everyone.” Albert Einstein said that. We ask that scientists who apply for funding to the Cancer Research Foundation prepare scientific documents for the rank and review process by other scientists, and an additional interpretation, paraphrased in lay language, for our trustees. In discussion at funding meetings, we are fortunate to have medical consultants who can further clarify these difficult



scientific concepts.

It has been said by scientists that the mammoth-size Human Genome Project will change the world when it is completed this year. The goal is to uncover the exact chemical sequencing, molecule by molecule, that constitutes the entire human “genome” or the entire set of

human DNA. Scientists will find out why some people get sick from certain illnesses while others do not. Then they can develop tests and treatments and cures.

One of the most significant aspects of the basic research that we fund is that advances in the understanding of fundamental processes usually lead to many types of practical applications. The research we fund in the laboratory will yield new tools and concepts that will provide the knowledge for scientists to develop a sophisticated plan to fix a “broken” genetic code - for any cancer.

And so, there is some urgency in funding the most promising research. One of our goals is to fund “bench to bedside” cancer research: translational research. The University of Chicago receives most of our major research support: their physicians and scientists are often the people who invent new approaches in the laboratories to change medicine for the better at the bedside.

In this issue of *Connections*, you will read about our support for five young investigators and one senior

“Chance favors only the mind that is prepared.”

Dr. Louis Pasteur



**CANCER
RESEARCH
FOUNDATION
FLETCHER
SCHOLAR:**

**Edwin L. Ferguson,
Jr. Ph.D.**

**“Isolation and Molecular
Characterization of Stem
Cells and Their Use in
Cancer Therapy.”**

Edwin L. Ferguson, Jr., Ph.D., University of Chicago Associate Professor in the Department of Molecular Genetics and Cellular Biology, has been named the Fletcher Scholar 2000. Dr. Ferguson, who chairs the Committee on Developmental Biology, and serves on the Committees on Genetics and Cancer Biology, is the sixth Cancer Research Foundation Fletcher Scholar.

The Fletcher Scholar Award was created by an endowment established by Eugene and Dorothy Fletcher, of Lemont, Illinois, as a part of their estate. Income earned from the endowment funds this \$100,000 grant to a senior cancer researcher to support a distinctive and timely laboratory research project.

“In every individual, certain cell types are replaced routinely throughout the adult life. There must be particular types of cells in an adult that are capable of continually dividing to generate classes of differentiated cells. Such cells, called adult stem cells, are undifferentiated cells that have a

dual capacity: they have the capability of undergoing a self-renewal division to produce two descendants like themselves, or they can divide to produce descendants that cease division and differentiate into a defined cell type.”

“In this research, I propose a series of novel experiments that should lead to our ability to culture a pure population of stem cells. If our experiments are successful, we will also be able to control the ability of the stem cell to undergo a self-renewal division or to differentiate. Thus, we will be in a position to ask, and answer, fundamental questions about stem cell renewal and differentiation.”

Dr. Anthony P. Mahowald, Louis Block Professor and Chairman of the Department of Molecular Genetics and Cell Biology, tells us that Dr. Ferguson “has established himself as one of the foremost developmental geneticists in the country and his work continues to break new ground in understanding mechanistic issues. Throughout his work, Dr. Ferguson has shown both amazing

Medical Ethics: A Transcribed Conversation

First broadcast on WBEZ Radio, FM 91.5, and printed with permission.

Part I was published in our April, 1999, newsletter.

Part II was published in our October, 1999, newsletter.

For a copy, please call our office, and we will mail it to you.

Identification of Participants:

VL: Victoria Lautman, WBEZ

MS: Dr. Mark Siegler, Professor in the department of Medicine at the University of Chicago, where he is also the founding director of the MacLean Center for Clinical Medical Ethics

AG: Ann Dudley Goldblatt, assistant director for the MacLean Center for Clinical Medical Ethics, who also teaches in the law school, the medical school and the college at the University of Chicago

VL: As if the terrain isn't complicated enough with all of these medical devices and treatments and life-prolonging types of technologies, you also have a whole slew of cultural and religious issues to deal with. How is that factored in? Does that play an important role in the discussions you have in these meetings?

AG: Yes because for example in different cultural groups sometimes you have a mother in law or a grandmother who is the decision maker and we sometimes get confused because we don't know why no one is willing to make decisions on behalf of the patient if the patient's incompetent – and then we learn that these are particular cultural distinctions. Sometimes we get wonderfully strange people that we weren't ready for who want a shaman to come in and provide prayers and that, of course, is fascinating and simplifies the problems, but we do get some international and cross-cultural problems for which we simply aren't

prepared until we're told about them.

MS: It's one of the fundamentals of the field of medical ethics that patient values are very important, and these values can be changed dramatically by different cultural backgrounds, different religious backgrounds, and at least to the extent that we encourage the doctors and the nurses to learn of their patient's background and values.

AG: I think actually we're becoming – I think perhaps people were a little scared – the physicians and the other healthcare workers were a little bit wary of medical ethicists for awhile, but I think they have come to see us as helpers as opposed to

MS: critics

AG: critics, yes, and actually most of the consults do come from the medical team – who seek answers to problems that individual patients or other people have brought to them; so I think we're seen as a help.

MS: And I'm not sure that, despite our efforts to publicize the availability of the service, that patients and families are entirely aware that ethicists are available at many hospitals around the country. Studies have shown that most hospitals of over 200 beds have some sort of ethics program, and the bigger hospitals have, as you say, even more formal programs. So patients are informed of that as part of the entrance to the hospital, but I suspect that many of them are not entirely aware of it and, if they are, they and their relatives might call upon the services of ethicists not just at our hospital but elsewhere.

VL: How open to litigation are you? Do you find that now that you're in there

MS: I'm against it.

VL: I know there are cases of ethicists, even medical teams, that have been sued by the family. Is that something you see that just goes with the territory?

AG: I myself am aware of very few, and I think it would be difficult to see, since we are consultants, that we have ever forced anyone to change their mind or done anything that was damaging to a family or a patient. I don't worry about it, do you, as an ethicist?

MS: As a physician I'm always aware of the litigation climate in our practice climate. But it turns out, as Mrs. Goldblatt says, that ethics consultation has not been one of the main sources of complaints against medicine. Because I think that many people realize that the ethics consultant is there to try to assist the patient and the family and the doctors to reach decisions that they want to reach and that are ultimately in the patient's best interest. There have been, as Mrs. Goldblatt says, a handful of cases against ethics committees that I've heard about around the country, but they tend to be really the exception to the general rule.

VL: We have a lot of people calling in; let's take a couple of phone calls right now. Jean, hello.

Jean: My name is Jean and I'm a family member of someone who died in the past year of chronic illness.

Young Investigator Awards

“GLUCOCORTICOID- MEDIATED SURVIVAL SIGNALING IN HUMAN MAMMARY EPITHELIAL CELLS”

\$50,000.

Dr. Geoffrey Green, Ph.D. in the Ben May Institute for Cancer Research, states that “the discovery of a link between glucocorticoid receptor activation and survival signaling is a potentially clinically relevant avenue of breast cancer research and will provide important additional data. ”

“ANALYZING THE ROLE OF HUMAN Y-CHROMOSOMAL GENES IN NORMAL DEVELOPMENT AND TUMORIGENESIS OF GERM CELLS”

\$50,000.

Dr. David Ledbetter, Marjorie I. and Bernard A. Mitchell Professor and Chairman of the Department of Human Genetics, tells us that “ Dr. Lahn is by all measures a truly remarkable young scientist and prominent rising star in his field. He was appointed Assistant Professor in the Department of Human Genetics on July 1, 1999, after a national search effort. He was very highly sought after by a number of other outstanding institutions. Dr. Lahn’s remarkable energy and productivity predict that he will continue a highly



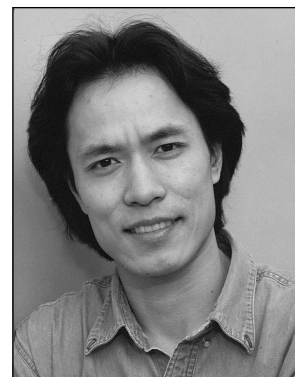
Jonathan P. Staley, M.D.

Assistant Professor
Department of Molecular Genetics and Cell Biology



Suzanne D. Conzen, M.D.

Assistant Professor
Department of Medicine



Bruce T. Lahn, Ph.D.

Assistant Professor
Department of Human Genetics

productive independent research program. “

Dr. Lahn is named the Raymond F. Zelko Young Investigator in

“THE ROLE OF AN ATPASE IN 5’ SPLICE SITE RECOGNITION”

\$50,048.

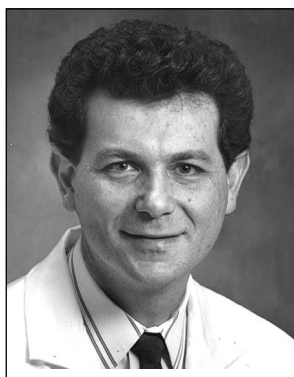
Dr. Anthony P. Mahowald, Louis Block Professor and Chairman of the Department Of Molecular Genetics and Cell Biology states: “The fidelity of splicing is absolutely critical for the faithful execution of genetic information. Dr. Staley’s work is innovative and provides a major new paradigm for understanding the fidelity (exactness) of splicing.”

**“ELIMINATION OF TUMOR
SPREAD BY CD4 + T CELLS”
\$50,000.**

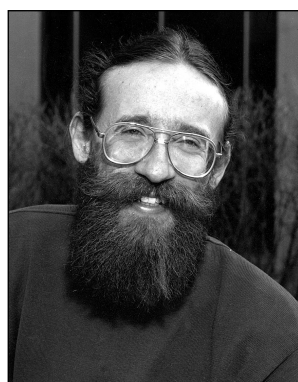
Dr. Bruce Gewertz, the Dallas B. Phemister Professor and Chairman of the Department of Surgery, says that “Dr. Shilyansky has distinguished himself as a superb technical surgeon, a dedicated researcher, and a role model for his colleagues and students. Joel is an innovative scientist whose research could lead to fundamental breakthroughs in cancer research.”

Dr. Hans Schreiber, Professor in the Department of Pathology tells us that “It would be critical to the biomedical community to develop the career of academic surgeon-scientists with broad-based knowledge in molecular cancer biology and immunology.”

“Dr. Shilyansky is the hardest worker I have seen in a long time and he has endless enthusiasm carefully



Joel Shilyansky, Ph.D.
Assistant Professor
Department of Surgery



Wouter Hoff, Ph.D.
Assistant Professor
Department of Biochemistry and
Molecular Biology

**“SIGNAL TRANSDUCTION BY A
BACTERIAL PHOTORECEPTOR”
\$50,000.**

Dr. Keith Moffat, Professor in the Department of Biochemistry and Molecular Biology, says that “Dr. Hoff has the potential to become a world leader in physical biochemistry,” that “he has a breadth of knowledge, arising from his training in a very broadly-based microbiology department and from his strong interest in interdisciplinary studies.”

October, 1999

Each year, the Cancer Research Foundation accepts grant requests from young men and women engaged in first-project laboratory and/or clinical cancer research. These proposals come to the Foundation already reviewed and ranked by a faculty awards committee, using the National Institutes of Health peer review process. Only the innovative and bold proposals with practicable research plans are considered for funding.

After receipt by the Foundation, our medical consultant, Dr. Joseph B. Kirsner, interprets the complex science to the trustees. Cancer Research Foundation trustees make all funding decisions.

Last October, five young scientists from the University of Chicago Medical Center were awarded young investigator grants:

- Suzanne D. Conzen, M.D.
- Wouter Hoff, Ph.D.
- Bruce T. Lahn, Ph.D.
- Joel Shilyansky, M.D.
- Jonathan P. Staley, Ph.D.

These awards are for one year. At the end of the year, if the hypotheses have proven worthy of further study this early research will be used as a basis for application for major outside funding.

Medical Ethics: A Transcribed Conversation

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I would like to say, after listening to your discussion, that with all due respect to the medical ethicists and the work that they do, in my experience and our family's experience, that any work that any medical ethicist may do, whichever decision they make, I feel that it will always be used in the current system of HMOs to deny care to patients. That has been our experience in our family, the struggle to get the care that the patient wanted.

AG: It certainly is true that perhaps the major ethical problem in the doctor-patient relationship right now seems to be denying care that either the patient or the family or, in some cases, in many cases, the doctor feel would be appropriate. As I say, we haven't had that kind of case come to us very often yet, and I think the problem is that it's very hard for your family members to figure out how you can actually advocate most strongly to get what you think is appropriate. And I'm hoping that the HMOs will become more accepting of these problems in the future, but I feel like President Clinton, I feel your pain, I know exactly what you're saying and I think that we should be more involved in these treatment denial considerations.

MS: Jean, it's interesting that you raise this question, because throughout the past twenty or thirty year history of medical ethics, the major problem has been quite the opposite, and that is the claim by patients and families that no one was listening to them when they said enough is enough and they wanted to stop treatment. It was Mrs. Goldblatt back in 1980 who, in a way, wrote the first essay which said that if you really take patients and families rights seriously to refuse

treatment when they think enough is enough, you have to be prepared to take them seriously when they request treatment when the doctors say enough is enough. And when we talk about 1980, we're talking about a time long before the managed care movement in this country. But I think what you've said, and what Mrs. Goldblatt has agreed with, is clearly the case, that in the last four or five years we've seen Mrs. Goldblatt's prediction coming true in the managed care setting, and that is the refusal of treatment that patients want or that families request has emerged as a major concern, and it's sad to hear that you and your family experienced that kind of a problem.

VL: What is an example of the kind of situation where that would actually take place, where there's a terminal patient who might be able to have a couple more costly treatments, and the ethicist is called in and says, well, basically this person is going to die, so why are we prolonging this situation? Have I made a right synopsis there? It's crude but

MS: No, it's a reasonable synopsis: all medical care plays on the notion of probability and the question that patients and families and doctors are often asking is "what is the likelihood, what is the probability of benefiting the patient by doing certain treatments," and let's say some of them are costly, expensive, treatments at the end of life. In the old days, if the probability were greater than zero, it's likely that the treatment would be offered to the patient, and the patient would have a right to make a decision to accept or not to accept the treatment. I think, in the more recent days where payers increasingly are controlling some of

those decisions, a probability perhaps of one in a thousand, or one in a five hundred, may not be something that payers are eager to support – particularly if it's a costly intervention and so, you get into this debate as to whose decision should it be? The patient? Or the family's? Or the doctor's? On the other hand, should it be the third party payer, whether it's a private payer like an HMO, or a public payer like government for Medicare or Medicaid?

VL: Do you ever - I wanted to know - are you ever uncomfortable with a decision that you make, even though, on the one hand, you know you've made the right decision? Are there cases also where you really think, gosh I wish I had that to do over again? Go on, you can answer that.

AG: I think very seldom, because we don't decide alone, and so we hear all the points of view, and I think all of us are tempered by the other points of view, and so we don't make as extreme a decision, and once again it is mediated by the family or the doctor once we've finished. So I would say I'm seldom uncomfortable; I'm frequently distressed by the tragedy that almost every one of these cases involves, the personal tragedy and sadness. So it's always distressing, but I don't frequently feel we've been unjust.

MS: No, I don't feel we've been unjust, but I tend to often be distressed about whatever decision we've reached, because by the time we're called in to reach a decision, both sides have substantial merit. It's not as if ethics is to decide between good and bad, right and wrong, it tends to be a struggle to decide between right and right, which makes it very difficult. And the other thing is that outcomes

Medical Ethics: A Transcribed Conversation

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often are important, that is, these cases don't end with the ethics consultation opinion; the case continues on to some sort of resolution and sometimes the resolution makes you re-think the ethics suggestion you had made weeks or months before.

AG: Right. I tell you what does distress me is the phone call, and one of the things I've thought about is, as we've learned about denying care, do we begin to trust the doctors less? And that means we begin to be more aggressive in what we ask for, and that exacerbates problems and maybe even creates problems? And that's sad.

VL: Jean, thank you for your question. Let's move on to another one. Jan, thanks for joining us on Odyssey.

Jan: Yes, this is the situation: A liver becomes available and a family would like to specify a recipient. Now, assuming the blood type is OK and the tissue typing, and it's a family member, well fair enough; but what if they would like to specify the recipient as being a celebrity - such as, and I don't

mean to use Walter, but that would be a situation. What if the family members would like to specify that the liver goes to Walter Payton?

VL: They will their liver to somebody specific?

Jan: Well, if there's a family member who dies in an accident, and a liver becomes available, and the remaining family members would like to specify the donor, it could be somebody in their family, but what if it were Walter, or somebody like that? Can a person do that? Can a family do that? And, of course, what are the repercussions of that?

VL: Thank you Jan.

MS: Obviously, this idea of directed donations is something that we permit, if not encourage, with regard to blood transfusions. Secondly, the use of living donors, say for kidney transplantation, is a common practice in this country. Probably kidney donors - living donors - account for 30-35% of the kidney transplants that are done in the United States. Now the question you're raising is whether a family can direct a donation of a cadaveric liver from a loved one in their family who has died, and although I was not aware of it until last week, apparently that is permissible. I did not know that

until I chatted with a few transplant surgeons last week, and so, there are provisions, as you say, whereby an organ could be directed to a specific individual. Generally, that might be someone in the family who needs a kidney transplant, for example, but I think there's nothing in the rules that would preclude the directed donation to an unrelated stranger, let's say a celebrity, like Mr. Payton.

AG: I'm not as positive about that. There have been cases where a young girl was killed in an accident, and her classmate needed a heart, and they permitted the directed donation. But, in general, the problem is, if you permit directed donations, do you also permit generic (no Asian Americans, no males, you know, this must go to a white caucasian female who's a member of Kappa Kappa Gamma) you know, you could get very specific. Obviously, that's very inappropriate. And so, I think, in general, a directed donation to a stranger, especially a non-celebrity, but I would say a celebrity, too, I think is suspect. It's unjust to the people who need the organs more, and who've been waiting longer.

Editor's note: This conversation will conclude in the next issue of Connections, Fall, 2000.

Special Occasion and Memorial Acknowledgement

Gifts honoring the memory of someone dear who has died, or gifts in celebration of birthdays, anniversaries, a new home, a new baby or many other special occasions arrive at the Cancer Research Foundation daily.

This represents a current philanthropic trend in gift giving. Caring individuals and companies are making donations to CRF in someone's name, in lieu of client or staff gifts. It's truly a way to demonstrate that it is better to give than to receive.

Now it's even easier to give. In addition to personal checks and cash, **you can charge your gift to VISA, MasterCard or American Express** - by mail, by phoning our office at (312) 630-0055, or online.

Online donations to the Cancer Research Foundation are run on a Secure E-Commerce Transaction Server. When you enter information on our website donation page, the information is encrypted before it gets sent over the Internet. The transaction remains 100% secured from everyone except you, the donor, and CRF.

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A SPECIAL GIFT TO THE CANCER RESEARCH FOUNDATION:

The MEDINAH MIDDLE SCHOOL students in Roselle, Illinois, had a winter carnival. The sixth, seventh and eighth grade students participated in the construction of game-booths, ticket sales, and running the event. The total monies raised, \$950.00, were

given to the Cancer Research Foundation, and designated for leukemia research, in memory of the father of one of the students.

We placed this contribution in the laboratory of Dr. Janet D. Rowley. Dr. Rowley is the Blum-Riese Distinguished Service Professor of Medicine and of Molecular Genetics and Cell Biology at the University of Chicago. She first discovered genetic abnormalities in the chromosomes of leukemia patients and has continued to research the chromosomes of cancer patients throughout her career. Dr. Rowley was awarded the nation's highest science award, the National Medal of Science, by President Clinton in 1999.

Information is on Your Computer.

The National Cancer Institute (NCI) puts information about its State-of-the-Science meetings on a Web site:

<http://www.conference-cast.com/webtie/sots/sots.htm>.

The meetings bring together small groups of clinical and basic scientists from industry, academia, the community, as well as patient advocates, for discussions on future clinical research opportunities.

Digital audio makes it possible to hear the presentations

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Cancer Research Foundation

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As a responsible member of the community, the Cancer Research Foundation believes in accountability. We think the more you know about our trustworthy stewardship of funds, the more willing you will be to invest in the future through the Cancer Research Foundation.

Every year, the Cancer Research Foundation files a report with the Internal Revenue Service, IRS Form 990 (Return of Organizations Exempt from Income Tax). This report is available for public inspection in our office.

We also make it available by mail, at a nominal cost.

Cancer Research Foundation financial records are audited annually by Grant Thornton. Their report is reprinted in its entirety and included each year in

The Cancer Research Foundation is an Illinois 501 (C) (3) not for profit corporation, operating in Chicago. Our mission is to help find the cures for cancer through research. We welcome memorial contributions and gifts in honor of special celebrations. Contributions are deductible to the full extent allowed by law.