

## HUMAN GENETICS FOR NON-SCIENTISTS: PRACTICAL WORKSHOPS FOR POLICY MAKERS AND OPINION LEADERS

### Abstract

These workshops form part of a series of workshops that the Banbury and the DNA Learning Centers of Cold Spring Harbor Laboratory have held for a number of years, introducing genetics, and the ways in which scientific research is done, to non-scientists. The purpose of the workshops as stated in the grant application was:

"Our objective is to foster a better understanding of the societal impact of human genome research by providing basic information on genetics to non-scientists whose professions or special interests interface with genetic technology.... Participants will be chosen for their interest in human genetics and for their roles as opinion leaders in their own communities. Primary care physicians are of particular interest to us for this series of workshops."

Two workshops were held under this grant. The first was held in 21-24 April, 1994 and attended by 20 participants, and the second was held 16-19 November, 1995, and attended by 16 participants. In each case, there was a combination of concept lectures on the foundations of human molecular genetics; lectures by invited specialists; and laboratory experiments to introduce non-scientists to the techniques used in molecular genetics.

### Participants

At present, the application of molecular human genetics is largely confined to tertiary health care centers that have access to the expertise of molecular geneticists, often associated with high level research groups. However, patients first contact primary care physicians and while the number of such patients is still relatively small, it will increase rapidly as genes associated with common disorders such as cancer are found. In addition, there is increasing public awareness of genetics amongst the public, as evidenced by the increasing coverage of genetics in all manner of publications. Thus primary care physicians—essentially non-scientists in regards to genetics—will play a crucial role in the application of human genetics in the coming years. For these reasons, we chose to target this group for our workshops, especially primary care physicians who do not have ready access to lectures, seminars and meetings in tertiary care facilities.

To this end, our colleagues at Huntington Hospital provided us with a list of program directors for continuing education in hospitals in New York State. We felt that this was an especially important group to invite, in the expectation that they would be encouraged to institute genetics education programs in their own institutions. In addition we invited two non-scientists whom we knew had a special interest in genetics—a broadcaster on Long Island and a freelance journalist writing a book on the biological basis of homosexuality.

DISTRIBUTION OF THIS DOCUMENT IS UNLIMITED

MASTER

## **DISCLAIMER**

This report was prepared as an account of work sponsored by an agency of the United States Government. Neither the United States Government nor any agency thereof, nor any of their employees, make any warranty, express or implied, or assumes any legal liability or responsibility for the accuracy, completeness, or usefulness of any information, apparatus, product, or process disclosed, or represents that its use would not infringe privately owned rights. Reference herein to any specific commercial product, process, or service by trade name, trademark, manufacturer, or otherwise does not necessarily constitute or imply its endorsement, recommendation, or favoring by the United States Government or any agency thereof. The views and opinions of authors expressed herein do not necessarily state or reflect those of the United States Government or any agency thereof.

## **DISCLAIMER**

**Portions of this document may be illegible  
in electronic image products. Images are  
produced from the best available original  
document.**

This workshop demonstrated an enthusiasm on the part of the primary care physician community, so for the second workshop we extended our invitations to the whole country. Invitees were selected from a nation-wide listing of directors of continuing education. We decided to limit invitations to mid-west and east because of the need to keep travel costs to a minimum. Care was taken to ensure that there were not more than two invitees from any institution and that wherever possible these were one male and one female. 215 invitations were mailed to institutions in 25 states. The meeting was attended by physicians from 9 states, including Arkansas, Kansas, Louisiana, North Dakota, Tennessee, and West Virginia.

The participants' lists for both meetings are attached.

## Program

Copies of the programs for the meetings are enclosed. They followed a similar format, one that we have found best suited for non-scientists.

**Concept Seminars:** Although the participants were physicians, we decided to treat them as non-scientists in regard to the fundamentals of genetics. This proved to be the correct decision. The first of these with a presentation began with an overview of Mendelian genetics, followed by a discussion of the eugenics movement in the early part of this century (intended as an historical introduction to a later talk by an invited speaker.) Participants were impressed to learn of Cold Spring Harbor Laboratory's involvement with eugenics. This was followed by a talk that went from DNA through gene structure, including splicing, "junk" DNA, gene families and DNA sequencing. The third concept seminar reviewed three topics that recur repeatedly in the genetics literature and are important in understanding how recombinant DNA techniques are used in mapping human genes. And, finally, how these same techniques are used to clone human disease genes.

**Feature Seminars:** These were given by eminent invited speakers who could talk to participants with authority. We organised them into three sets. The first set of two talks dealt with practical issues in the clinical use of human genetics:

cytogenetics . . . . . Susan Airhart  
Brian Ward

difficulties of genetic counselling . . . Patricia Ward

The latter was especially appreciated. The second set of talks discussed genetic advances in clinical problems. These included:

Cancer Genetics . . . . .	Curt Harris
Gene Therapy . . . . .	Ken Culver
	Charles Link
Alzheimer's Disease . . . . .	Rudi Tanzi
Genetics of Obesity . . . . .	Jeffrey Friedman

Fragile-X syndrome . . . . . Ted Brown  
Genetics of Psychiatric Disorders . . . . . Melvin McInnis

The third set discussed controversial issues and we felt were especially important in alerting these primary care physicians to the notion that genetics is not going to be a panacea and is going to require very careful use:

Genetics and Behavior . . . . . Tim Tully  
Future of Genetic Testing & Screening . . . Philip Reilly  
Genetics & Cultural Attitudes to Disability . . . Marsha Saxton

**Laboratory Experiments:** Participants perform recombinant DNA experiments of the kind done in research laboratories. The few failures at even these simple experiments are a salutary reminder that doing such experiments is not merely a matter of following a recipe. The two experiments are:

Using restriction enzymes to construct a genetic map  
DNA fingerprinting using the polymerase chain reaction

### **Assessment of Workshop**

We enclose copies of letters from participants in the two workshops. It is clear that the workshops were beneficial and achieved their goal of exciting and informing primary care physicians about modern human genetics. Several refer to the implementation of genetic teaching in their institutions. The importance of the workshop was self-evident for one participant who received an invitation to be chair of an IOM on *Genetics, Health and Behavior* in the week following the workshop. In addition, Jan Witkowski was invited to speak at three of the participating hospitals.

### **Conclusion**

These workshops demonstrate that primary care physicians are enthusiastic to learn about modern human genetics and that they will use what they have learned. Furthermore, physicians will travel considerable distances for these workshops. It is clear that this is a very worthwhile and effective method of educating an important section of the medical community. The challenge that faces us is to translate the kind of program that we can do here at Cold Spring Harbor Laboratory, into a program that can be used around the country.

# HUMAN MOLECULAR GENETICS - A HANDS-ON WORKSHOP

## Banbury Center and DNA Learning Center Cold Spring Harbor Laboratory

Organizers: Mark Bloom, DNA Learning Center  
David Micklos, DNA Learning Center  
Jan Witkowski, Banbury Center

---

### THURSDAY, 21 APRIL

Afternoon	Arrival at Robertson House, Banbury Center for registration and room assignment
6:00 pm	Reception at Robertson House
7:00 pm	Dinner at Robertson House

---

### FRIDAY, 22 APRIL

7:30-8:45 am	Breakfast, Robertson House
8:55-9:00 am	Welcome and Introduction
9:00-9:45 am	<i>Concept Seminar:</i> <b>Mendelian View of the Gene - From Peas to Eugenics</b> David Micklos
9:45-10:30 am	<i>Concept Seminar:</i> <b>Modern view of the Gene</b> Jan Witkowski
10:30-11:00 am	Break
11:00-11:45 am	<i>Concept Seminar:</i> <b>PCR, RFLPs and (CA)<sub>n</sub>: What they are; what they do</b> Jan Witkowski
11:45-12:15 pm	<b>Questions &amp; Discussion</b>
12:30-1:30 pm	Lunch at Robertson House
1:45-2:30 pm	<i>Feature Seminar</i> <b>Cytogenetics in the Age of DNA</b> Susan Airhart, Oncor Science, Gaithersburg, Maryland

2:30 pm Bus to DNA Learning Center

2:45-5:00 pm *Laboratory Part I:*  
**Using Restriction Enzymes to Construct Chromosome Maps**  
David Micklos

5:00 pm Tour of Cold Spring Harbor Laboratory

5:45 pm Bus to Banbury Center

6:00 pm Reception at Robertson House

6:30 pm Dinner at Robertson House

8:00 pm *Laboratory Part II:*  
**Construction of Chromosome Map**  
David Micklos

---

## SATURDAY, 23 APRIL

7:15-8:15 am Breakfast, Robertson House

8:30-9:15 am *Concept Seminar:*  
**Cloning Human Disease Genes**  
Mark Bloom

9:15-10:00 am *Feature Seminar:*  
**DNA-based Diagnosis for Human Genetic Diseases**  
Patricia Ward, Institute of Molecular Genetics, Baylor College of Medicine, Houston, Texas

10:00-10:30 am Break

10:30-11:15 am *Feature Seminar:*  
**Cancer Genetics - New Advances, New Surprises**  
Curtis Harris, Laboratory of Human Carcinogenesis, National Cancer Institute, Bethesda

11:15-12:00 pm *Feature Seminar*  
**Molecular Genetics & Biology of Alzheimer's Disease**  
Rudolph Tanzi, Neurogenetics Laboratory, Massachusetts General Hospital, Boston

12:00-12:15 pm	<b>Questions &amp; Discussion</b>
12:30-1:30 pm	Lunch at Robertson House
1:30 pm	Bus to DNA Learning Center
1:45-4:30 pm	<i>Laboratory:</i> <b>Fingerprinting Your Own DNA by Polymerase Chain Reaction</b> Mark Bloom; David Micklos
4:30-5:30 pm	<b>Visit to Cold Spring Harbor Laboratory</b>
5:45 pm	Bus to Banbury Center from Cold Spring Harbor Laboratory
6:00 pm	Reception at Robertson House
6:30 pm	Dinner at Robertson House

---

## SUNDAY, 24 APRIL

7:15-8:15 am	Breakfast, Robertson House
8:30-9:00 am	<i>Laboratory Results:</i> <b>Analysing Fingerprinting Results</b> Mark Bloom; Dave Micklos
9:00-9:45 am	<i>Feature Seminar:</i> <b>Human Gene Therapy Trials</b> Charles Link, Human Gene Therapy Institute, Des Moines, Iowa
9:45-10:30 am	<i>Feature Seminar:</i> <b>Genetics and Behavior</b> Tim Tully, Cold Spring Harbor Laboratory
10:30-11:00 am	Break
11:00-11:45 am	<i>Feature Seminar:</i> <b>Genetics and Cultural Attitudes to Disability</b> Marsha Saxton, Massachusetts Office on Disability, Boston
11:45-12:30 pm	<i>Feature Seminar:</i> <b>Future of Genetic Testing and Screening</b> Philip Reilly, Shriver Center for Mental Retardation, Waltham, Massachusetts

12:30 pm      **Closing remarks**

12:45 pm      **Lunch**

**Afternoon Departure**

---

## HUMAN GENETICS: DOE WORKSHOP

The Banbury Center, Cold Spring Harbor Laboratory, 21-24 April 1994

### PARTICIPANTS

**Susan Airhart**  
Oncor, Inc.  
209 Perry Parkway  
Gaithersburg, MD 20877  
(301) 963-3500, x359  
(301) 926-6129 fax

**Jak Albukerk**  
Southside Hospital  
48 Buttonwood Drive  
Dix Hills, NY 11746  
(516) 499-0425  
(516) 499-0425 fax

**Kurt Altman**  
863 Park Avenue  
New York, NY 10021  
(212) 288-9062  
(212) 230-8099 fax

**Judah Bauman**  
7 Overdale Court  
Huntington, NY 11743-6810  
(516) 271-8535

**Mark Bloom**  
DNA Learning Center  
Cold Spring Harbor Laboratory  
Cold Spring Harbor  
NY 11724  
(516) 367-7240  
(516) 367-3043 fax

**Chandler Burr**  
826 Aspen Street, N.W.  
Washington, D.C. 20012  
(202) 291-0545  
(202) 291-0857 fax

**Mitchell Charap**  
New York University School of Medicine  
530 First Avenue, Suite 7B  
New York, NY 10016  
(212) 263-7442  
(212) 263-8995 fax

**Sridhar S. Chilimuri**  
Department of Medicine  
Bronx-Lebanon Hospital Center  
1650 Grand Concourse  
Bronx, NY 10457  
(718) 518-5812  
(718) 518-5830 fax

**Shyan-Yih Chou**  
Division of Nephrology & Hypertension  
The Brookdale Hospital  
Medical Center  
Brooklyn, NY 11212  
(718) 240-5615  
(718) 485-4064 fax

**J. Dwek**  
La Guardia Hospital  
102-01 66th Street  
P.O. Box 16  
Forest Hills, NY 11375  
(718) 830-4359  
(718) 830-4362 fax

**Lawrence Fultz**  
Department of Medicine  
New York Hospital Medical Center  
of Queens  
56-45 Main Street  
Flushing, NY 11355  
(718) 670-1070  
(718) 358-1196 fax

**Howard S. Friedman**  
Department of Medicine  
Long Island College Hospital  
340 Henry Street  
Brooklyn, NY 11201  
(718) 780-1881  
(718) 780-1300 fax

Curtis C. Harris  
National Cancer Institute, NIH  
Bldg. 37, Rm. 2C01  
9000 Rockville Pike  
Bethesda, MD 20892  
(301) 496-2048  
(301) 496-0497 fax

Charles T. Hennings  
634 Park Avenue  
Huntington, NY 11743  
(516) 427-1242  
(516) 549-3933 fax

Daniel Kenigsberg  
625 Belle Terre Road  
Suite 200  
Port Jefferson, NY 11777  
(516) 331-7575  
(516) 331-1332 fax

Charles Link  
Human Gene Therapy Institute  
Iowa Methodist Medical Center  
1415 Woodland Avenue  
Des Moines, IA 50309

Paul S. Mandala  
Good Samaritan Hospital Medical Center  
1111 Montauk Highway  
West Islip NY 11795  
(516) 422-3800  
(516) 665-8098 fax

Joseph S. Matrisciano  
Franklin Hospital Medical Center  
900 Franklin Avenue  
Valley Stream NY 11580  
(516) 825-8800 x 2007  
(516) 285-5741 fax

David Micklos  
DNA Learning Center  
One Bungtown Road  
Cold Spring Harbor, NY 11724-2219  
(516) 367-7240  
(516) 367-3043 fax

Patrick Montelione  
St. Francis Hospital  
100 Port Washington Blvd.  
Roslyn, NY 11576  
(516) 627-4800  
(516) 627-8484 fax

Andrew Packard  
Huntington Hospital  
180 East Pulaski Avenue  
Huntington, NY 11746  
(516) 425-2160  
(516) 425-2193 fax

Philip Reilly  
Shriver Center for Mental Retardation  
200 Trapelo Road  
Waltham, MA 02254  
(617) 642-0230  
(617) 894-9968 fax

Bernard M. Rosof  
Office of Medical Affairs  
Huntington Hospital  
270 Park Avenue  
Huntington, NY 11743  
(516) 351-2647  
(516) 351-2586 fax

Marsha Saxton  
Project on Women & Disability  
Massachusetts Office on Disability  
1 Ashburton Place, Room 1305  
Boston, MA 02108  
(617) 277-5617  
(617) 727-0965 fax

Robert Scheig  
Department of Medicine  
Buffalo General Hospital  
100 High Street  
Buffalo, NY 14203  
(716) 845-1258  
(716) 845-1491 fax

Melba Tolliver  
News 12 Long Island  
One Media Crossways  
Woodbury, NY 11797  
(516) 496-1771  
(516) 496-1456 fax

Patricia Ward  
DNA Diagnostics Laboratory  
Institute for Molecular Genetics  
Baylor College of Medicine  
Houston, TX 77030  
(713) 798-6534  
(713) 798-6584 fax

Jan A. Witkowski  
Banbury Center  
Cold Spring Harbor Laboratory  
P. O. Box 534  
Cold Spring Harbor, NY 11724-0507  
(516) 549-0507  
(516) 549-0672 fax

Rudolph Tanzi  
Neurogenetics Laboratory  
Massachusetts General Hospital  
22 Fruit Street  
Boston, MA 02114  
(617) 726-6845  
(617) 726-5735 fax

Tim Tully  
Cold Spring Harbor Laboratory  
1 Bungtown Road  
P.O. Box 100  
Cold Spring Harbor  
NY 11724-2213  
(516) 367-8875  
(516) 367-8880 fax

David Westring  
Department of Academic Affairs  
Nassau County Medical Center  
2201 Hempstead Turnpike  
East Meadow, NY 11554  
(516) 542-3881  
(516) 542-5793 fax

# HUMAN MOLECULAR GENETICS - A HANDS-ON WORKSHOP

Banbury Center and DNA Learning Center  
Cold Spring Harbor Laboratory

Organizers: Mark Bloom, DNA Learning Center  
David Micklos, DNA Learning Center  
Jan Witkowski, Banbury Center

---

## THURSDAY, 16 NOVEMBER

Afternoon	Arrival at Robertson House, Banbury Center for registration and room assignment
6:00 pm	Reception at Robertson House
7:00 pm	Dinner at Robertson House

---

## FRIDAY, 17 NOVEMBER

7:30-8:45 am	Breakfast, Robertson House
8:55-9:00 am	Welcome and Introduction
9:00-9:45 am	<i>Concept Seminar:</i> <b>Mendelian View of the Gene - From Peas to Eugenics</b> David Micklos
9:45-10:30 am	<i>Concept Seminar:</i> <b>Modern view of the Gene</b> Jan Witkowski
10:30-11:00 am	Break
11:00-11:45 am	<i>Concept Seminar:</i> <b>PCR, RFLPs and (CA)<sub>n</sub>: What they are; what they do</b> Jan Witkowski
11:45-12:15 pm	<b>Questions &amp; Discussion</b>
12:30-1:30 pm	Lunch at Robertson House
1:45-2:30 pm	<i>Feature Seminar</i> <b>Cytogenetics in the Age of DNA</b> Brian Ward, Integrated Genetics, Inc., Waltham, Massachusetts

2:30 pm Bus to DNA Learning Center

2:45-5:00 pm *Laboratory Part I:*  
**Using Restriction Enzymes to Construct Chromosome Maps**  
David Micklos

5:00 pm Tour of Cold Spring Harbor Laboratory

5:45 pm Bus to Banbury Center

6:00 pm Reception at Robertson House

6:30 pm Dinner at Robertson House

8:00 pm *Laboratory Part II:*  
**Construction of Chromosome Map**  
David Micklos

---

## SATURDAY, 18 NOVEMBER

7:15-8:15 am Breakfast, Robertson House

8:30-9:15 am *Concept Seminar:*  
**Cloning Human Disease Genes**  
Mark Bloom

9:15-10:00 am *Feature Seminar:*  
**DNA-based Diagnosis for Human Genetic Diseases**  
Patricia Ward, Institute of Molecular Genetics, Baylor College of Medicine, Houston, Texas

10:00-10:30 am Break

10:30-11:15 am *Feature Seminar:*  
**The Genetics of Obesity**  
Jeffrey Friedman, Howard Hughes Medical Institute, The Rockefeller University

11:15-12:00 pm *Feature Seminar*  
**Molecular Genetics & Biology of the Fragile-X Syndrome**  
W. Ted Brown, Dept. of Human Genetics, NYS Institute Basic Research, Staten Island, New York

12:00-12:15 pm **Questions & Discussion**

12:30-1:30 pm Lunch at Robertson House

1:30 pm	Bus to DNA Learning Center
1:45-4:30 pm	<i>Laboratory:</i> <b>Fingerprinting Your Own DNA by Polymerase Chain Reaction</b> Mark Bloom; David Micklos
4:30-5:30 pm	<b>Visit to Cold Spring Harbor Laboratory</b>
5:45 pm	Bus to Banbury Center from Cold Spring Harbor Laboratory
6:00 pm	Reception at Robertson House
6:30 pm	Dinner at Robertson House

---

## SUNDAY, 19 NOVEMBER

7:15-8:15 am	Breakfast, Robertson House
8:30-9:00 am	<i>Laboratory Results:</i> <b>Analysing Fingerprinting Results</b> Mark Bloom; Dave Micklos
9:00-9:45 am	<i>Feature Seminar:</i> <b>Genetics and Behavior</b> Tim Tully, Cold Spring Harbor Laboratory, New York
9:45-10:30 am	<b>Genetics of Psychiatric Disorders</b> Melvin McInnis, Dept. of Psychiatry, Johns Hopkins University, Maryland
10:30-11:00 am	Break
11:00-11:45 am	<i>Feature Seminar:</i> <b>Human Gene Therapy Trials</b> Ken Culver, OncorPharm, Inc., Gaithersburg, Maryland
11:45-12:30 pm	<i>Feature Seminar:</i> <b>Future of Genetic Testing and Screening</b> Philip Reilly, Shriver Center for Mental Retardation, Waltham, Massachusetts
12:30 pm	Closing remarks
12:45 pm	Lunch
	Afternoon Departure

---

# HUMAN GENETICS: DOE WORKSHOP

The Banbury Center, Cold Spring Harbor Laboratory, 16-19 November 1995

## PARTICIPANTS

Mark Bloom  
DNA Learning Center  
Cold Spring Harbor Laboratory  
Cold Spring Harbor  
NY 11724  
(516) 367-7240  
(516) 367-3043 fax

Robert W. Bradsher  
Internal Medicine  
Slot 639, University of Arkansas  
for Medical Sciences  
4301 W. Markham  
Little Rock, AR 72205  
(501) 686-5585  
(501) 686-8188 fax

Aloysius B. Cuyjet  
United Hospitals Medical Center  
15 S. 9th Street  
Newark, NJ 07107  
(201) 268-8389  
(201) 482-3073 fax

Ilise Levy Feitshans  
Columbia University School of Law  
5355 Henry Hudson Parkway  
Riverdale, NY 10471  
(718) 549-6235  
(718) 549 6235 fax

Rong J. Guan  
St. Luke's Hospital  
111 Amsterdam Avenue  
Dept. of Medicine  
New York, NY 10025  
(212) 523-5678  
(212) 523-3683 fax

Martin F. Heyworth  
VA Medical & Regional Office Center  
2101 Elm Street  
Fargo, ND 58102  
(701) 232-3241, ext. 3502  
(701) 298-0134 fax

George J. Kaloyanides  
Division of Nephrology & Hypertension  
Health Sciences Center  
State University of New York  
at Stony Brook  
Stony Brook, NY 11794-8152  
(516) 444-2038  
(516) 444-6174 fax

*KAPELNER*  
Stephen N. Kaptner  
St. John's Episcopal Hospital  
327 Beach 19th Street  
Far Rockaway, NY 11691  
(718) 868-7672  
(718) 327-8948 fax

Kara H. V. Kvilekval  
Department of Surgery, Health  
Sciences Center  
State University of New York  
at Stony Brook  
Stony Brook, NY 11794-8191  
(516) 444-2040  
(516) 444-8824 fax

Ernest Lieber  
Genetics Department  
Methodist Hospital of Brooklyn  
506 Sixth Street  
Brooklyn, NY 11215I-9008  
(718) 780-3258  
(718) 780-3085 fax

David Micklos  
DNA Learning Center  
One Bungtown Road  
Cold Spring Harbor, NY 11724-2219  
(516) 367-7240  
(516) 367-3043 fax

Shawn Milligan  
School of Medicine in Shreveport  
Louisiana State University  
Medical Center  
1501 Kings Highway, P.O. Box 33932  
Shreveport LA 71130-3932  
(318) 424-6042  
(318) 424-6179 fax

John A. Oates  
Department of Medicine  
Vanderbilt University School of Medicine  
D-3100 MCN  
Nashville, TN 37232-2358  
(615) 322-3146  
(615) 343-7550 fax

Andrew Packard  
Huntington Medical Group  
180 East Pulaski Avenue  
Huntington, NY 11746  
(516) 425-2160  
(516) 425-2191 fax

Asghar Rastegar  
Department of Medicine  
Yale University School of Medicine  
1074 LMP  
333 Cedar Street  
New Haven, CT 06520  
(203) 737-2078  
(203) 785-7030 fax

Philip Reilly  
Shriver Center for Mental Retardation  
200 Trapelo Road  
Waltham, MA 02254  
(617) 642-0230  
(617) 894-9968 fax

Myra Skluth  
Norwalk Hospital  
87 East Avenue  
Norwalk, CT 06851  
(203) 866-4455  
(203) 866-9113 fax

Daniel J. Stechschulte  
Kansas University Medical Center  
Department of Medicine - Room 4035 Wescoe  
3901 Rainbow Blvd.  
Kansas City, KS 66160-7317  
(913) 588-6008  
(913) 588-3995 fax

Tim Tully  
Cold Spring Harbor Laboratory  
1 Bungtown Road  
P.O. Box 100  
Cold Spring Harbor  
NY 11724-2213  
(516) 367-8875  
(516) 367-8880 fax

Brian E. Ward  
Integrated Genetics  
1 Mountain Road  
Framingham, MA 01701

Kevin Yingling  
Marshall University School of  
Medicine  
1801 Sixth Avenue, Rm. 308  
Huntington, WV 25703  
(301) 696-7242  
(301) 696-7267 fax

W. Ted Brown  
Dept. of Human Genetics  
NYS Institute Basic Research  
1050 Forest Hill Rd.  
ten Island NY 10314-6399  
(718) 494-5363  
(718) 494-1026 fax  
wtbibr@aol.com

Kenneth W. Culver  
Director of Gene Therapy Research and Clinical  
Affairs  
OncorPharm, Inc.  
200 Perry Parkway  
Gaithersburg, MD 20877  
(301) 926-4400  
(301) 208-6997 fax  
kculver@oncorpharm.com

Jeffrey M. Friedman  
Howard Hughes Medical Institute  
The Rockefeller University  
1230 York Avenue, Box 305  
New York, NY 10021-6399  
(212) 327-8800  
(212) 327-7420 fax  
friedj@rockvax.rockefeller.edu

Melvin McInnis  
Dept. of Psychiatry & Behavioral Sciences  
The Johns Hopkins Hospital  
600 North Wolfe Street, Meyer 3-181  
Baltimore, MD 21287-7381  
(410) 955-8370  
(410) 614-1530  
mmcinnis@pennsy.med.jhu.edu

Philip Reilly  
Shriver Center for Mental Retardation  
200 Trapelo Road  
Waltham, MA 02254  
(617) 642-0230  
(617) 893-5340 fax  
preilly@shriver.org

Timothy Tully  
Cold Spring Harbor Laboratory  
1 Bungtown Road  
P.O. Box 100  
Cold Spring Harbor NY 11724-2213  
(516) 367-8875  
(516) 367-8880 fax  
tully@cshl.org

Brian Ward  
Integrated Genetics, Inc.  
1 Mountain Road  
Framingham MA 01701  
(508) 872-8400  
(508) 879-6236 fax

Patricia Ward  
DNA Diagnostics Laboratory  
Department of Molecular Genetics  
Baylor College of Medicine  
Houston TX 77030  
(713) 798-6534  
(713) 798-6584 fax  
pward@bcm.tmc.edu



# GOOD SAMARITAN HOSPITAL MEDICAL CENTER

1000 Montauk Highway • West Islip, Long Island, NY 11795

May 26, 1994

Jan A. Witkowski, Director  
Banbury Learning Center  
P.O. Box 534  
Cold Spring Harbor, NY 11724-0534

Dear Jan,

First of all, please excuse the fact that I have been so late in sending you this note to say, "Thank You". I did certainly want to send you a note to express my sincere thanks for what was probably one of the most scientifically interesting weekends of my life!

I graduated from medical school 33 years ago and since graduation, my knowledge of genetics has been limited only to what I have read and what I have been able to pick up on my own through my reading. Certainly the idea of bringing the physicians who are medical educators to the Learning Center to get, as it were, "brushed up" on the current advances in genetics is a marvelous one and should be continued.

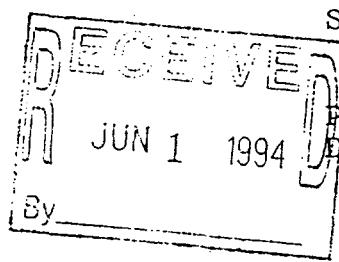
The entire weekend was an unforgettable experience not only for the learning part of it, but also for the comradery which was shared at that time and the sense of closeness which developed between some of the members of the class and the instructors. The instructors were extremely helpful and interesting and the informality of it all lent itself extremely well to learning more than one could ever obtain in a rather formal and stiff way.

Jan, wouldn't it be interesting to see how many "older" doctors would be interested in a program of this type at some point during their continuing medical education careers?

Again, I would like to say "thank you", for a lovely weekend and I hope that I can be invited again some time to continue this.

Sincerely,

Paul S. Mandala, M.D.  
Director, Graduate Medical Education



PSM:nvm



UNIVERSITY AT BUFFALO  
STATE UNIVERSITY OF NEW YORK

Robert Scheig, M.D., Head  
Department of Medicine  
School of Medicine  
Faculty of Health Sciences  
Buffalo General Hospital  
100 High Street  
Buffalo, New York 14203  
(716) 845-2272

May 2, 1994

Jan Witkowski, Ph.D.  
The Banbury Center  
Cold Spring Harbor Laboratory  
P.O. Box 534  
Cold Spring Harbor, NY 11724-0534

Dear Jan:

I wanted to thank you for the superb course you conducted for us in medical education last week. It was a thoroughly enjoyable time in which I gained a lot of new knowledge and which I think I will be able to put in practice in the teaching programs here in Buffalo for our medical students and housestaff. You assembled a superb group of speakers and I was particularly struck by those of you at the DNA Learning Institute who conducted several sessions for us. I hope I may return in the future for some of your other courses.

Sincerely yours,

Robert Scheig, M.D.  
Professor of Medicine  
Program Director

RS/ajp



ONCOR, INC.  
209 Perry Parkway Gaithersburg, MD 20877

301-963-3500

Fax: 301-926-6129

April 25, 1994

Dr. Jan Witkowski  
Banbury Center  
Cold Spring Harbor Laboratory  
P.O. Box 534  
Cold Spring Harbor NY 11724-0534

Dear Jan:

Enclosed are all of the various receipts for the trip to present at the Human Molecular Genetics Workshop on April 22, 1994.

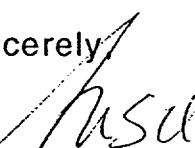
Airfare - \$300  
Limo - \$150  
Parking - \$10  
~~\$460~~

I think your program to educate the primary care physicians is extremely important and that you are doing a great job. It is so difficult to explain this technology to someone who isn't familiar with the language. Would you mind if I used your car analogy for polymorphism? I thought that one was great.

It was good to see you again and I hope its not quite so long until our next visit.

OK to pay \$460.00  
Suzanne Oliver 5/2/94  
592-00-540/B62110

Sincerely

  
Susan Airhart  
Director, Molecular Cytogenetics

✓

VANDERBILT UNIVERSITY



NASHVILLE, TENNESSEE 37232

TELEPHONE (615) 322-5000

School of Medicine • Department of Medicine • Direct Phone (615) 322-3384  
FAX (615) 343-7550

December 4, 1995

Jan A. Witkowski, Ph.D.  
Director  
The Banbury Center  
Cold Spring Harbor Laboratory  
P.O. Box 534  
Cold Spring Harbor, NY 11724-0534

Dear Jan,

I would like to thank you for the opportunity to participate in the workshop on Human Molecular Genetics the Banbury Center. The scientific content of the workshop was exceptionally well presented as was its societal context.

Given the objective of the workshop, you will be interested to see (attached) the request that arrived on my desk the week following the workshop. I would hope to be able to call on you and your colleagues for advice as the work of the Committee on Genetics, Health, and Behavior: Science in Perspective progresses.

With best regards,

Sincerely,

A handwritten signature in cursive script, appearing to read "John".

John A. Oates, M.D.  
The Thomas F. Frist, Sr. Professor  
and Chairman

JAO/ksf

enclosure



DEPARTMENT OF MEDICINE  
School of Medicine  
1801 Sixth Avenue  
Huntington, West Virginia 25703-1585

*Copy sent to Jan, Dr. Witkowski*

INTERNAL MEDICINE RESIDENCY PROGRAM  
304/696-7242  
304/696-7297 FAX  
  
Kevin W. Yingling, M.D.  
Program Director  
Associate Professor of Medicine  
and Pharmacology

November 22, 1995  
*Joyce A. Ray  
Program Coordinator*

Lana G. Smith  
Secretary

Jan Witkowski  
The Banbury Center  
Cold Spring Harbor Laboratory  
P O Box 534  
Cold Spring Harbor, NY 11724-0534

Dear Dr. Witkowski:

Please accept my deepest appreciation for the opportunity to participate in the Human Molecular Genetics-Hands on Workshop conducted November 16-19, 1995. My activities in this workshop and the information I received during the workshop are unparalleled regarding personal satisfaction and stimulation in an educational activity. The group from the DNA Learning Center and Banbury Center were outstanding. I attend many conferences across the country on a yearly basis. Clearly, the learning atmosphere, educational spirit, collaboration, camaraderie, and general good will of your program separates your program from all other learning activities I have participated in in the past several years.

I return to my home institution energized to continue my education regarding molecular genetics and its use in my practice of clinical medicine. I remain energized to begin to encourage students, residents and faculty regarding curricular issues in this area, as well as personal input regarding use of molecular genetics in clinical medicine.

Again, thank you for the opportunities provided to me during the workshop. I am deeply appreciative and plan to use this information in a positive manner over the next several years.

Sincerely,

A handwritten signature in black ink, appearing to read 'K.W. Yingling'.

Kevin W. Yingling, MD  
Associate Professor of  
Medicine & Pharmacology  
Program Director

KWY/ls

P.S. Please find enclosed my expense voucher. Information regarding that issue can be forwarded to me at the above address.

# The University of Kansas Medical Center

School of Medicine  
Department of Internal Medicine  
Division of Allergy, Clinical Immunology  
and Rheumatology

Daniel J. Stechschulte, M.D., Director  
K.N. Dileepan, Ph.D.  
Herbert B. Lindsley, M.D.  
Karen M. Simpson, M.D.  
Kathryn E. Welch, M.D.

November 21, 1995

Nurse Clinicians  
588-3929  
Tracey Castelman, R.N., B.S.N.  
Nadine Colbert, R.N., B.S.N.  
Glenda Virtue, R.N.

Jan Witkowski, Ph.D.  
The Banbury Center  
Cold Spring Harbor Laboratory  
P.O. Box 534  
Cold Spring Harbor, NY 11724-0534

Dear Jan:

I appreciated the opportunity of participating in the Human Genetics: DOE Workshop. I felt it was well run and it was certainly a stimulating experience for me. Best wishes.

Sincerely,



Daniel J. Stechschulte, M.D.  
Professor of Medicine  
Director, Division of Allergy,  
Clinical Immunology & Rheumatology

DJS/gns

Enclosure - Expenses Voucher

# Southside Hospital

301 East Main Street  
Bay Shore, NY 11706-8458  
516-968-3000

May 2, 1994

The Banbury Center  
Cold Spring Harbor Laboratory  
PO Box 534  
Cold Spring Harbor, NY 11724-0534

Attn: Jan A. Witkowski, Director

Dear Dr. Witkowski:

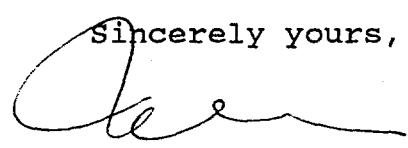
I wish to thank you, your staff and the Center for providing me the opportunity to participate in an outstanding seminar on genetics which was well planned with no effort or resources spared.

This undertaking is particularly difficult for a group with heterogeneous interests. It is also remarkable that the seminar tried to counter-balance genetics with social and environmental issues. In my belief, the latter two topics were not contributory.

In the overall, it was a most exciting experience.

With best wishes,

Sincerely yours,

  
Jak Albukerk, M.D.

Enclosure

# Long Island Fertility & Endocrinology

## IVF Associates PC

(516) 331-7575

DANIEL KENIGSBERG, MD

LI  
IVF



April 28, 1994

Jan Witkowsky, Ph.D.  
Director, Banbury Center  
P.O. Box 534  
Cold Spring Harbor, NY 11724-0534

Dear Dr. Witkowsky:

I would like to express my appreciation for allowing me to participate in the program "Human Molecular Genetics - A Hands On Workshop" at Banbury Center and the DNA Learning Center, Cold Spring Harbor Laboratory. The organization and quality of teaching were excellent; well beyond the quality of any post graduate course that I have ever attended.

Specifically, the intramural faculty of David Micklos, Mark Bloom, and yourself are excellent teachers of this complex material and harked back to my experiences over 20 years ago at an elite American university that prides itself on instruction as well as research. The obvious dedication and patience in explaining every aspect of this field was greatly appreciated by this participant.

The extramural faculty was also very good with exceptional lectures by Rudolph Tanzi from Massachusetts General Hospital and Charles Link from the Human Gene Therapy Institute in Iowa. As a physician, these two lecturers both gave me an in-depth appreciation of how one might approach a clinical or scientific problem with DNA technology and then how that technology might be potentially applied in a research and eventual clinical setting.

In closing, I can say that without reservation that the experience of participating in this course will forever positively change my understanding of the biological sciences and my practice of medicine.

Again thank you for allowing me to participate.

Best regards,

Daniel Kenigsberg, M.D.

DK/cjm

April 26

Dear Jan,

Thanks for the great conference! Now I have to sift through all the paper and notes I took and find out what I learned, sort of a process of consolidating the information in my brain. I need sticky glial cells so it all sticks in there.

These are the questions I was going to ask you up there, but it's just as well we do it this way. Can we set a date for a phone conversation? Take a look at this, and then, maybe next week? I'll call you and find out a good time.

I'll be in San Francisco May 19-25, and was thinking of going down to Stanford Monday, Tues, or Wed (23-25). That's when Botstein and I are tentatively set up. I'm going to try to get Cox to talk to me then. What should I ask both of them? And is there anyone else?

Again, thanks. I'll talk to you soon.

Chandler

A handwritten signature in cursive ink, appearing to read "Chandler".



# THE BROOKDALE HOSPITAL MEDICAL CENTER

Linden Boulevard at Brookdale Plaza • Brooklyn, New York 11212-3198 • (718) 240-5615

Affiliated with  
State University of New York,  
Health Science Center at Brooklyn  
and New York University  
College of Dentistry

Division of Nephrology  
and Hypertension

May 4, 1994

Dr. Jan A. Witkowski  
Banbury Center  
Cold Spring Harbor Laboratory  
P.O. Box 534  
Cold Spring Harbor, N.Y. 11724-0534

Dear Dr. Witkowski:

It has been more than a week since I left Cold Spring Harbor Laboratory, yet the impact on me of spending 3 days learning molecular biology from the scratch at the Laboratory has not diminished a bit. The Human Genetics: DOE Workshop is the most exhilarating learning experience I have ever had in my life. I could not imagine that there is any place in the world more conducive to learning than The Banbury Center/Cold Spring Harbor Laboratory. The program was extremely well planned, thoughtful, and above all, vital for physicians engaged in education in teaching other physicians or lay people to understand the importance of advancing molecular biology.

Before I attended the workshop, I had rudimentary knowledge about genetics and knew nothing of techniques used to study genes. I bore prejudice against molecular science largely due to ignorance. As a matter of fact, many of my colleagues share my view or have no interest of understanding molecular biology. This workshop simply changed me; I am now firmly convinced that curing diseases will depend on understanding disease at the molecular level.

I work in a teaching hospital with more than 1000 beds. I was fortunate to be able to attend the workshop because our director of medicine, Dr. Lyon, had to attend a meeting sponsored by American College of Physician during the week of the workshop. After we returned from the meeting, he inquired me of the workshop and was quite excited about it. He now plans for me to give a few talks about what I have learned from the workshop to house-staff and attending physicians at our hospital. I look forward to this exciting assignment.

Lastly, I would like to express my thanks to all staff at the Banbury Center for making this workshop so inspiring.

Sincerely,

Shyan-Yih Chou, M.D.

Professor of Medicine



**LaGuardia Hospital**  
102-01 66th Road, Forest Hills, NY 11375  
(718) 830-4000

Friday, 29 April 1994

Ms. Jan Witkowski  
Banbury Center  
Cold Spring Harbor Laboratory  
P.O. Box 534  
Cold Spring Harbor, NY 11724

Dear Jan,

This letter is intended to express my appreciation of the course on Human Molecular Genetics, which I was privileged to attend. It had a profound effect on my understanding of the subject, and the clinical implications. It was superbly organized; the speakers were outstanding; the interactions most valuable.

I do hope to be able to transmit some of this to our residency program and would be most pleased if you would accept invitations to participate in our basic science seminars, during the 1994-95 academic year.

Sincerely,

*Joe*  
Joe Dwek, M.D.  
Program Director  
Internal Medicine Residency Program

JD/js



HOWARD S. FRIEDMAN, M.D.

CHAIRMAN, DEPARTMENT OF INTERNAL MEDICINE  
PROFESSOR, SUNY HEALTH SCIENCE CENTER AT BROOKLYN

THE LONG ISLAND  
COLLEGE HOSPITAL  
BROOKLYN, NY 11201  
718-780-1881  
FAX 718-780-1300

April 26th, 1994

Jan Witkowski  
The Banbury Center  
P.O. Box 534  
Cold Spring Harbor  
N.Y. 11724-0534

Dear Jan:

I would like to express my appreciation to you, Mark and David for your informative and enjoyable conference. It was an extraordinary experience for me. I will be applying what I learned almost immediately, since, as I mentioned to you, the current methods of testing for tuberculosis based on clinical findings, acid fast smears, and cultures are inefficient in identifying patients with this disease. I hope to apply PCR for the early and accurate diagnosis of this disease.

I would also like to invite you to give Medical Grand Rounds at Long Island College Hospital so that the residents and attending staff could be given an update in the advances of molecular genetics. I would like you to give three conferences next year. These are held on Thursday morning, from 11:30 to 12:30. One conference would introduce the basics of molecular genetics and the techniques used, such as PCR and RFLP. Another would be devoted to the application of these methods in medicine: recombinant DNA, gene therapy, and its use for screening and testing. The third conference would be devoted to the ethical, legal and social implications of molecular biology, perhaps, with a historical perspective, discussing eugenics, similar to that presented at the conference. An honorarium of \$500.00 would be given. If you agree, I would suggest dates, perhaps, on three consecutive Thursdays.

Again, I would like to thank you, David, Mark, and Katya for three wonderful days.

Sincerely,

  
HOWARD S. FRIEDMAN, M.D.

HSF:df

CHARLES T. HENNINGS, M.D., P.C.  
634 PARK AVENUE  
HUNTINGTON, L. I., N. Y. 11743  
TELEPHONE HA 7-1242

CHARLES T. HENNINGS, M.D., F.A.C.S.

May 5, 1994

Jan A. Witkowski  
Banbury Center  
Cold Spring Harbor Laboratory  
P.O. Box 534  
Cold Spring Harbor, N.Y. 11724-0507

Dear Jan,

Enclosed you will find the survey for the DOE Sponsored Workshop on Human Genetics and Genome Analysis which took place April 22-24, 1994. Along with this survey, I wanted to take a brief moment of your time to Thank You and, when I say you, I am including Drs. Micklos and Bloom.

When I first heard of the workshop, I was hoping to come away from the weekend with a basic understanding of both the Genetics and Genome Analysis but I have to say that the workshop was much more than that to me. You and your staff, as well as all of the guest speakers, were absolutely fantastic. Even though, those of us who were in attendance had a scientific background, many of us were neophytes in our understanding of our Genetics. With the combination of discussions and laboratory workshops it became obviously clear how all these basic science projects are so important to all of us in our society. I am particularly pleased that the Department of Energy sponsored this workshop and would only be too happy to write to anyone in the Department of Energy who is involved in this sponsorship. The natural extention of this type of educational workshop is for those of us to understand the importance of a national effort to extend this type of teaching to the basic science labs of Junior High School and High Schools.

I can not Thank You enough and I will always remember this weekend as perhaps being the best scientific program that I have attended in the past 20 years.

Sincerely,



Charles T. Hennings, M.D.

CTH:eam

CC: Mark Bloom, DNA Learning Center  
David Macklos, DNA Learning Center