Cancer Patients Denied Access To Data on ‘Alternative’ Cures

Any cancer patient — or family member, friend, or physician — can get usable, up-to-date scientific information on experimental treatments by dialing 1-800-4-CANCER. This is the number for PDQ, the cancer hotline maintained by the National Cancer Institute (NCI).

If, however, the caller wants comparable scientific information about “alternative” or “unconventional” cancer therapies, PDQ is no help. It doesn’t have the data. Neither does the American Cancer Society (ACS) hotline, or any other publicly or medically accessible on-line database or phone service.

This is not because this potentially life-or-death information doesn’t exist. It does — in great detail. Several thousand pages of it. It is called the Evaluative Database on “Unproven and Untested” Cancer Remedies.

The problem is, no one can see or use it.

Fears Cited

The reason: threats and the risk of lawsuits by alternative and unconventional practitioners, according to the database’s developer and co-owner, Washington, D.C., lawyer and patient advocate Grace Ann P. Monaco, J.D. She said last month by phone that alternative practitioners’ political pressure, through Congress, also is a factor.

NCI ordered the database, and paid $500,000 to Monaco and her associates, under a publicly-funded research grant, to compile it. But the agency refuses to accept the product as a gift and make it available to PDQ users, for whom it originally was designed.

“We . . . feel that the peer-reviewed information that it contains is potentially quite valuable for physicians who are counseling patients about these approaches,” NCI oncologist Michael J. Hawkins, M.D., told Monaco by letter on August 16, 1991. Hawkins, who then was chief of the investigational drug branch in NCI’s cancer therapy evaluation program, went on to explain that the database would have to be updated (which NCI does continually for PDQ). So, he said, the federal agency would be “willing to accept it only if we were able to keep it at its current high level.”

Based on cost projections, Hawkins added, “the NCI is reluctant to commit the resources that would be required to maintain your database in an adequate fashion. Therefore we do not feel it is appropriate to accept it as a gift.”

A PDQ administrator at NCI, Judy Patt, added last month in a phone interview: “I remember a lot of letters from congressmen” opposing the project.

Cancer Society Drags Feet

The ACS has been similarly reticent: It acknowledges the data’s instant value to cancer patients and their doctors, but has not been willing to make it available.

“We don’t have any information on alternative methods,” an ACS service operator said last month, in response to a query on its hotline, 1-800-ACS-2345.

The NBC-TV program, “The Crusaders,” reported (Oct. 23, ’93) that ACS would accept the data, and offer it to the public. Over a year later, however, the cancer service organization has failed to do so. In a “Dear Grace Ann” letter received last month, the chief of ACS’s Questionable Methods Subcommittee, Richard Lange, M.D., told Monaco that the organization continues on page 6
Reviewing PROBE's Agenda:

Attack on Science and Reason
Is Our Big Story — Thus Far

This PROBE starts our fourth year of publication. We're pleased to have reached this juncture, and grateful to you, our readers, for bringing us here.

We note that it's been a long time since we last reviewed — and updated — our editorial agenda (PROBE, April '92, April '93).

We would like to seize this moment to do so, particularly since some readers have asked how we choose the stories we write. A bit of history points to the specifics: PROBE was conceived in the spirit of I.F. Stone's Weekly. We worked for Stone, briefly, in 1956. More important, we read — and admired — his work for more than two decades.

Compass Folds

Stone was a political writer and an iconoclast; he also was a leftist. He started his newsletter when the New York Compass, the last newspaper that was willing to publish his column, folded in 1954.

Unlike Stone, we try to be apolitical. Some people say, nevertheless, that we're too left, or too right. We think of ourselves as a rad-con, or, at other times, as an old-fashioned liberal. More important, our task, like Stone's, is to challenge prevailing opinion and the established media that shapes it.

The news beat we learned over time is medicine and science. But, like Stone, we often found that what we judged to be important stories and ideas, based on our reporting, were not welcome in the mainstream media in which we worked — even as a column of opinion. What is more, there still is no regular journalistic op-ed column on science and medicine in any major U.S. daily paper as far as we know.

The media is not ready to have science critics. We're trying to lead the way. We're hoping to show our science writer colleagues and their editors and publishers that a columnistic approach — personal journalism — is a feasible, doable, and much needed element in reporting on medicine and science.

Unable to place PROBE as a newspaper column (we had written 40 pilots), we decided to take the extraordinary — some said foolhardy — risk of self-publishing our work, as Stone did.

News Counts

Like Stone's newsletter, PROBE is a news publication. We believe we can serve readers best by digging out new stories and presenting new ideas and fresh points of view. Our aim, like the milkman's, is to bring you a product that always is fresh.

So: PROBE is committed to covering the events and ideas that the mainstream press ignores, deliberately or not. Particularly, since we are a small, infrequent publication, we search for what we believe to be scientifically and journalistically important long shots. We're willing to take the short end of 95 to 5 cases, even the 99 to 1’s. The balanced stories — the 50-50 "he said, she said" stories — we leave to our mainstream colleagues.

This is not to say that we don’t aim to "Get it right!" We absolutely do!

The search for promising long shots has guided our coverage and led us to what we think is this decade's most important science story: the attack on science, and rationality, which undergirds both science and the democratic political process.

We are not here to defend science and reason. PROBE's mission is to analyze, and, where appropriate, attack their continued on next page
Agenda ...

continued from preceding page

tackers. PROBE is the only publication, inside or outside of science, that focuses its journalistic effort on investigating the attack on science and reason.

Coverage Explained

This focus should explain our continuing coverage of the Gallo and Baltimore/Imanishi-Kari scientific misconduct cases, and the Public Health Service’s Office of Research Integrity (ORI), the agency responsible for them. For the same reason, we have focused on the political patron (until recently) of these attacks, Congressman John D. Dingell (D - Mich.), and his journalistic outriders, particularly John Crewdson of the Chicago Tribune.

The anti-science attacks of the '90s remind us, chillingly, of the “anti-subversive” witch hunts of the '50s. We also think that the current anti-scientism expresses deeper impulses in our society of disappointment, frustration, and rage. We hope to help in the understanding of these treacherous currents. We hope to help turn them around.

We are very worried about ideological and political intervention in science. This meddling is particularly damaging — and wrong — in cases where technological solutions that could resolve major social problems are squelched for irrational reasons.

A major case in point: replacing the existing hypodermic syringes and needles with more advanced models that would only injecting once, then self destruct, and so could not transmit AIDS. This public health step might eliminate one major arm of the AIDS epidemic.

This option has been obvious for a decade. The technology is well within reach. But it is not being deployed. AIDS continues to spread as the result. This is societal self-destruction at its worst.

We want to ask, as loudly and pointedly as we are able to: Who is responsible when a technical solution that could serve society is ignored in this way?

Science and medicine stand with democracy, we think, in defense of human rights. Irrationalist cultural and ideological forces often stand against them. The paradigmatic story we are following here is female genital mutilation (FGM). Social upheaval in Africa and migration are bringing it to the U.S.

Do Institutions Respond?

The question we are trying to ask in our coverage is: How well will our institutions respond to this cultural threat, given that it is personally harmful, and denies its victims the individual right to pleasure, through genital sexuality. We believe this right should be protected by the Constitution’s promise of “life, liberty and the pursuit of happiness.” How well, we ask, are our institutions and, particularly, advocacy groups like the feminists, responding to the FGM threat?

Poorly, we think.

These are some of the issues PROBE presently is pursuing at the volatile interface between science and society. Genetic research and engineering is another. We are looking for other, still unrecognized sore points on the body politic or the corpus of medical and scientific knowledge and practice that might usefully be lanced by a sharp journalistic probe.

Quackery in medicine and nutrition come under our purview. First, because it is directly and expensively harmful to huge numbers of people.

More important, rules and rituals about what we do — or do not — ingest, and how, gain a powerful hold on people in turbulent times such as these. Nutritional irrationality and quackery have become powerful cudgels for ideologists and entrepreneurs: They use them to beat down rational and scientific approaches to nutrition and health to sell their worthless nostrums. Nutritional fraud is the main mass market force in the current attack on science and reason.

The media’s role in purveying bad science and anti-science to the public particularly concerns us, since we are part of the media. We also have the advantage of knowing something about how it works. PROBE is the only publication that features media criticism of science reporting.

This is PROBE’s agenda.

We hope, finally, that PROBE readers who share our concerns will tell us by letter or by phone (212-647-0200) of Probable topics that they encounter. All tips of course are confidential.

— David R. Zimmerman

Thanks Are Due!

The help and cooperation of a growing number of supporters has kept PROBE afloat and, we trust, on course! As we start our fourth publishing year, they have our heartfelt thanks:

The stalwarts listed with us on the masthead — Angela Darling, Tom Gilgut, and Veva Zimmerman — have remained steadfast through difficult times. Not listed there are Susan Hansen, our skillful copy editor, and Selma Davidowitz, who has recently undertaken some of the production chores. They, too, are stalwart!

Our colleague Lynne Lamberg graciously provides an annual index; this year’s will be published soon. Doris Margolis helps us reach many colleagues and VIP readers in Washington.

We enjoy enormous collegial support, and much helpful advice from Ted Klein, at Ted Klein & Co., and Ken Goldstein at the Columbia University Graduate School of Journalism.

We are particularly grateful to bioethicist John Fletcher, at the University of Virginia, and Irene Crowe, of the Pettus-Crowe Foundation, for helping us navigate a difficult bottleneck last summer, and extend our circulation. Paul Sperry and James Metzger made it possible for us to reach out to new readers — and grow.

Dorothy Magrif and Scott Parker have provided information and counsel, as have several other people whom we must thank here anonymously. We are grateful to you!

Max Greenberg and the Globe Mail agency, our excellent printer, have stuck with us. Thank you!

Our fellow newsletterist Tony Goldfarb of Medical Abstracts is a continuing source of encouragement.

Above all, we are thankful to you — our readers — for your continuing interest!

— D.R.Z.

January 1, 1995
Consumers Left Unprotected By New Food Law

A new federal law on dietary supplements — which include vitamins, minerals, herbs, and amino acids — is a disaster for consumers, for science, for truth-in-marketing, and also for the Food and Drug Administration (FDA), which must administer the measure.

The law thoroughly legitimizes the $4 billion a year market for dietary supplements, which it defines vaguely as substances for "increasing the total dietary intake." It was enacted as the Dietary Supplement Health and Education Act of 1993, and signed into law by President Bill Clinton in October (Public Law 103-417).

This law undermines consumer protection by taking the burden of proof from the manufacturer, who does not have to prove that a food supplement product is either safe or effective, to the FDA: The agency must go to court and prove a product is dangerous in order to remove it from the market.

Products Abound

Congress estimates that there are 4,000 food supplement products on the market. FDA's budget is tight, and its priorities are drug approval and regulation. So the odds on regulatory action against dietary supplements — barring an acute threat to public health, under which FDA can act promptly — may now be virtually nil.

Even assuming that some of these products are of health value, the consumer is left with the problem of deciding how much of which one he or she needs. For that, of course, consumers thus are left with no reliable guide to these products — few of which are demonstrably useful.

The new law is described by its Senate sponsor, Republican Orrin G. Hatch of Utah, a leading herb-growing state, as a "compromise." Negotiations in committee did in fact tighten the bill's product labeling segments. But it still is a major triumph for the nutritional supplements industry, which is described, approvingly, in the legislation as "an integral part of the [U.S.] economy . . . that consistently projects a positive trade balance."

The same can be said for cigarettes.

Some 600 companies make and market dietary supplements, the law says.

The Act codifies into law the supplements industry's spurious claim that their products are important for "health promotion and disease prevention."

Dietary supplements are not foods per se, but rather are capsules, powders, softgels, concentrates, and extracts, such as, for example, herbal extracts. (The law appears to legitimize "herbs" as health products for the first time under federal law.)

The law thus establishes a huge class of legal products that stand somewhere between foods and drugs. They aren't exactly food, because specific food chemicals may be concentrated hundreds or thousands of times in them. They aren't drugs, by definition.

Food Is Better

But then, why do half of adult Americans buy and use these products, as Congress says that they do? Not, apparently, purely for nutritional purposes, since most Americans who eat reasonably well easily obtain almost all required nutrients — as described in the National Research Council's Recommended Daily Allowances (RDA's) and FDA's Reference Daily Intakes (RDIs). And, if they don't, most nutritionists agree, people would be far better off spending money on whole food, rather than on the more costly and nutritionally less complete supplements.

The supplements' purposes, as codified in the Act, include "improving the health status of U.S. citizens," and helping consumers "avoid the excessive costs of traditional medical services."

But, with a very few exceptions — such as calcium to prevent osteoporosis, and folic acid to prevent severe birth defects — there is no scientifically accepted evidence that these products improve anyone's health. Rather, the evidence, or lack of it, suggests that this expenditure, encouraged under the new law, is simply money wasted.

The law trumps the safety issue for the manufacturers. It declares "dietary supplements are safe within a broad range of intake, and safety problems . . . are relatively rare."

The health food industry, which sponsored this bill — telling consumers, untruthfully, that FDA was going to forbid them to buy vitamins (PROBE, August) — thus is laughing on the way to the bank.

Congress did its bidding.

Congressional Analysts

The Congressional Research Service in the Library of Congress last month released an analysis of the new Dietary Supplement Health and Education Act. It includes these comments:

"While there is an ever-increasing body of evidence that nutrition in general, and specific nutrients in particular are important to health promotion and disease prevention, no such evidence has been provided for the use of dietary supplements per se. Although the findings [cited in the Act] allude to supplement safety, only a few supplement ingredients have been subjected to extensive scientific evaluation to determine their safety or the validity of their roles in disease prevention or treatment."

"The . . . [Act] seem[s] to suggest that there is no limit on
Pumped Up Claims Sell Muscle Bulkers

Congress has legitimated nutritional supplements, proclaiming them healthful a priori. Many of these products are promoted to weight-lifters and other athletes, and to health-conscious consumers as energy boosters and muscle builders. Do these supplements work? How? Science writer Russ Wild, of Allentown, Pa., checked out the stores and asked sports medicine experts. Here’s his report:

Hang a right at the Gap. Turn left at Thom McAnn’s. Follow the shopping maze till you get to your local Generic Nutrition Center. Walk in, and behold!

From every direction, powdered, liquid, and tablet supplements beckon you with promises of big, nasty, sledgehammer muscles. And who could resist?

“Outrageous Results,” growls one such product, Russian Bear.


“Gives you a blast of unrelenting power,” boasts Cyberblast. “Muscle growth while you sleep,” claims Opti-Genetics. And if you’re inclined to hoist a super-sized can of Super Natural, you’ll find promises of “more muscle, more power, more energy, and less body fat.”

Will they really do what they say? Will any supplement help you build muscles? If so, which ones?

Can Kelp Help?

Pick up one of these cans and read the label: couch grass, corn silk, grapefruit powder, cider vinegar, yohimbe, boron, ginseng, bee pollen, Chinese herbs, Mexican sarsaparilla, saw palmetto, wild yam, juniper berries, kelp . . . Shirley MacLaine’s cupboard.

All these New Age curiosities have one thing in common:

“They don’t do a thing,” says Jerry Attaway, who is physical development coordinator for the San Francisco 49ers. A dozen other experts — including exercise physiologists, nutritionists, and biochemists — agree. But does that mean that products with names like Monster 1100, Hot Stuff, Gainer’s Fuel, Mega Mass, Hardboy, and Gorilla won’t help you gain muscle mass? No, not at all! Chances are — provided you’re putting in time and sweat at the gym — that they will.

Ingredient Revealed

Bewildered? Don’t be. These oh-so cleverly named supplements do contain a “secret ingredient” — although its not one of those mentioned above. Neither is it the amino acids, or “pre-digested proteins,” “special metabolic optimizers,” or the “new anabolic growth formulas.”

Rather, the active muscle-building ingredient in all of these supplements is one that is not always emblazoned on the label, or highlighted in the ads. The ingredient that almost certainly will enlarge you, and possibly help you forge added muscle is: old-fashioned calories.

“If you give extra calories to the body, in whatever form, you will push the system to produce muscle and fat,” says Gail Butterfield, Ph.D., R.D., a sports nutritionist at the Palo Alto Veterans Affairs medical center in California. Whether your nutritional “push” results in wanted muscle, or in unwanted fat, will depend on how much and how often you exercise, she adds.

Calories of course come in many different forms. Which are best? Every single one of the experts interviewed agreed:

In most cases for most Americans, any supplemental calories should come from foods like spaghetti, bread, potatoes, and rice — all high in carbohydrates, low in fat, and limited in protein.

Eating these foods and exercising diligently will help you build a strong and healthy body. It doesn’t come in a can.

Says the 49ers’ Jerry Attaway:

“In most cases the purpose of any [muscle building] aid is to take money out of your pocket, and put it in somebody else’s!”

Criticize Nutritional Supplements Law

the substances that could be considered to be supplementing the diet, and therefore [would be] exempt from regulation as food additives or drugs. Given FDA’s resource constraints, the exemption from the food additive provisions of the Food, Drug & Cosmetics Act may make it considerably more difficult for FDA to challenge products for which there is a health or safety question.”

“There has never been a comprehensive review of supplement products and their ingredients.”

“No . . . objective source [of information] is currently available for amino acid and herbal products.”

“While there are, undoubtedly, supplement ingredients that have beneficial health effects for certain conditions, few, if any, of these ingredients have been subjected to systematic randomized clinical trials in the U.S.”

“There is no requirement to verify that the portion of [an] herbal product stated to be present in the supplement is that portion which is actually present. The lack of verification arguably creates the potential for fraud, abuse, and health problems, as . . . portions of some herbs are hazardous to health.”

“The supplement industry favors a weaker standard than significant scientific agreement [the FDA standard for foods and drugs] for the authorization of health claims for their products.”

This law was passed by a Democratic Congress. One can only wonder what will go down under the Republicans!
Censorship in Cyberspace: Internet Blocked

We are reminded incessantly that we live — bountifully — in the information era. Virtually no notice is given to the reality that information often is blocked — denied to needful recipients — by lawsuits or the threat thereof, or by ideological or political pressure.

The censorship of Grace Monaco's database on unconventional cancer therapies is a strong case in point. The information it contains can shape cancer patients' life or death decisions. So, it is critically important that major health and information sources act, in concert if need be, to see that this database becomes widely available. This means, in essence, putting the data up in an accessible file, and protecting it from meddling and legal challenge by quacks and their cliques.

The agencies that need to deal with this, to protect their own integrity as well as the public's health, include, of course, the federal government and the American Cancer Society. Also, major professional groups like the American Medical Association, and information companies like CompuServe.

The database was developed under rigorous guidelines (See story, below), and subjected to peer review. Given an update, which should not take long, it therefore has standing as a unique and valuable information source. The failure to make it accessible would be a marked failure for the health information community.

It also would represent a very serious blow to informational freedom on the Internet.

— D.R.Z.

Cancer...

continued from page 1

Database Was Created

With Scientific Rigor

Compilers of the database of unproven cancer treatments evaluated published scientific and nonscientific reports, and descriptive literature and claims from purveyors of these methods in the U.S., Mexico, the Bahamas, and other foreign sites. The information includes scientific validity, costs, the therapists' credentials, clinic locations, and evaluations of them by other scientific and medical groups.

Biochemical methods assessed included antineoplasms, bacterial vaccines, DMSO, the Greek cancer cure, immunoaugmentive therapy and half a dozen other approaches. Macrobiotics and other nutritional methods were evaluated, as were iridology and homeopathy. An overview was started, but not finished, on psychoneuroimmunology. Reviews were prepared, but have not yet been peer reviewed, on 15 herbal/botanical treatments such as black seed, chapparal tea, red clover and tang-kuei, an oriental herbal preparation.

Biochemist Saul Green, medical sociologist Barrie R. Cassileth, Ph.D., of Chapel Hill, North Carolina, quack-busting psychiatrist Steve Barrett, M.D., and several other experts prepared the reports on each method, with help from attorney Monaco and a physician consultant. Each method report then was sent to a peer review panel. They judged each write-up for accuracy and also for clarity, and returned them to the writers for improvements when necessary.

These steps all were taken in a scientifically rigorous manner, according to the final report on the grant — which was accepted by NCI.

bases and hope to develop information that would be appropriate for use through the [ACS] Cancer Response System database. The cost to maintain your database is a major issue which has not been resolved.

Monaco, and the project's scientific director, biochemist Saul Green, Ph.D., of New York City, a retired Memorial Sloan-Kettering Cancer Center scientist, call the cost issue a red herring. Annual update expenses for the entire database, of several thousand pages, would be minimal, they say — less than what one uninformed patient might pay for a course of worthless unconventional cancer treatment.

Green, who compiled much of the data, estimates that updates would take at most one full month of research and entry time per year. Monaco's estimate is that, once current, the database can be maintained for $60,000 per year — which, she suggests, might easily be found, once a major agency decides to take it.

The real issue, she insists, is the opposition.

The alternists' fears were summed up in New Age Journal (Sept./Oct.'89), at a time when they had temporarily blocked NCI's grant, claiming that Monaco had a conflict of interest because she is a consultant to insurance companies. The New Age magazine, under a headline "Database or Blacklist?" said:

"[I]f critics from the alternative medical community are correct, the objective assessment of alternative therapies that you're expecting PDQ to provide might instead end up functioning as a virtual electronic blacklist against nonconventional treatments. The reason, these critics charge, is that [Monaco] . . . seems to have, at best, a clear grudge against alternative cancer therapies and, at worst, a vested interest in steering cancer patients away from them."

Monaco responded, in her final report to NCI:

Promoters of 'unproven methods' [e.g., laetrile and immunoaugmentive therapy in the '70s and '80s] have brought suits to neutralize the activities of peer review and investigation of 'unproven methods.' So far, none of these [suits] has been successful.
Research rectitude 101:
Are Nobelist's Bad Manners a Case Of Misconduct?

This is a quiz:

Last year's winner of the Nobel prize for chemistry, Kary Mullis, Ph.D., was invited to speak recently at the European Society for Clinical Research meeting in Toledo, Spain. Mullis won the Nobel gold for discovering PCR, the polymerase chain reaction. This method has become as important for genetic analysis of DNA as baking powder is for making biscuits.

As he rose to speak in Toledo, Mullis told the Society's president, John F. Martin, M.D., of Utrecht, Holland, that he wouldn't talk about PCR. Rather, he would explain why he thinks AIDS is not caused by the virus called HIV.

The speech was "rambling" and the content was "inappropriate for a public appearance of a leader of science," Martin complains, in an angry letter to Nature (Sept. 8):

"His only slides (on what he called his 'art') were photographs he had taken of naked women with colored lights projected upon their bodies."

Mullis, according to Martin, accused science of being "universally corrupt, with widespread falsification of data to obtain grants . . . . [H]e claimed [that he] himself . . . changed data points . . . to make data-sets appear more significant . . . [to] illustrate that the practice is a common one."

Mullis "impugned the personal honesty" of several leading AIDS researchers by name. But, Martin said, "his own explanation [for AIDS] was incoherent and insubstantial." Martin said he stopped Mullis, and asked him three questions on AIDS.

"His reply was again inappropriate intellectually and in style."

Martin writes that Mullis said several times that winning the Nobel prize gave him authority to speak. Martin said this authority covered PCR, but not AIDS.

"Mullis not only decreased the nobility of the prize, but his attitude was, I believe, a potential corrupting influence on young scientists."

Reached by phone at his home in California, Mullis said Martin's letter was "totally inaccurate." He blamed the flap on Martin's — and Nature's — animosity to anyone who disbelieves, as he does, the hypothesis that HIV causes AIDS.

Mullis said the nudes were not his only slides. "I don't have continued on next page

Cancer . . .

continued from preceding page

However, defense against such suits, even unsuccessful or unfounded ones, can be costly. Prudent business practice requires that all risks be insured against. The cost of liability insurance to cover this risk is unaffordable by a small company. We continue to explore various vehicles for transferring the data to an agency, association, or organization that can handle the liability issue.

She reiterated her concerns last month by phone:

"The alternative providers don't want you to tell what you know about their products," she said. "That would interfere with their business."

Unconventional therapists claim to favor patients' freedom of choice.

But, she added, angrily:

"It's not freedom of patient choice that they want. It's freedom to give patients what they choose to give them as treatment!"

Monaco and her associates say they have never revealed the database's contents. So, they add, their opponents have censored the information sight unseen.

"This has always been what was to me the most shocking part of the experience," Monaco said. "Because none of the people who wrote in, trying to get our [NCI] grant unfunded has ever seen the material we have worked on. It was a perfect attempt at prior restraint."

"Unfortunately for us, it succeeded!"

"[Mullis] accused science of being "universally corrupt, with widespread falsification of data to obtain grants . . . . [H]e claimed [that he] himself . . . changed data points . . . to make data-sets appear more significant . . . [to] illustrate that the practice is a common one.""

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Compilers Have Top Credentials

Attorney Grace Monaco has sterling inside-the-beltway credentials, including awards and honors from the American Cancer Society and the Food and Drug Administration.

She became interested in cancer care when her four-year-old daughter, Kathleen, died of leukemia 25 years ago. She and the parents of other childhood cancer patients formed a national organization, called the Candlelighters Foundation, which provides support — including information on both proven and unproven therapies — for families of kids with cancer. Candlelighters now has 400 chapters, serving 35,000 children and kin.

The database is an effort to extend information to adult patients with cancer and their families. Monaco also has started a for-profit Medical Care Ombudsman Program to provide such information (202-544-1696).

The principal investigator and co-owner on the database grant was psychologist Beth Barnett, Ph.D., of Silver Spring, Md. The scientific director, biochemist Saul Green, Ph.D., did much of the research. He, too, provides information on unproven cancer therapies on a proprietary basis: 212 957-8029.

Why Quacks Err

"The problem with . . . . alternatives is not merely that they lack a sound biological basis; purely empirical treatments have occasionally been successful. What betrays their fundamentally irrational character is their proponents' failure to subject their therapeutic claims to controlled empirical testing."


January 1, 1995
time to deal with stuff like that," he added. "I'm not looking for [Martin's] approval, or for Nature's!"

How, then, should Mullis' performance be evaluated? We

Scientists of the World...

"[I]t is 'bourgeois' science that is real, objective science, while the 'subjective' science of our [Russian] Populists and the 'class' science of our Marxists are more like a form of faith than science."


don't know him. But we do know that he has a reputation among colleagues of being a wild man. That notwithstanding, if Martin's letter is accurate, he appears to have been rude. Crude. Arrogant. Disrespectful. Defamatory.

Should his Nobel prize therefore be repossessed? If so, should his research papers be withdrawn — expunged from the literature — because he has admitted that he sometimes cheated, and thus sullied science? Should PCR, and all of the research and forensic uses of it — including analysis of the O.J. blood stain data — be recalled? Thrown out as tainted?

Well, of course not! Because PCR's validity has been tested and confirmed by hundreds, perhaps thousands of Mullis' scientific colleagues. PCR is real science. It works. Its validity is independent of Mullis' personality.

The rest of it — the rudeness writ large — doesn't much matter. A scientist's misconduct outside the lab is not *ipso facto* scientific misconduct.

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