CONFIDENTIALITY AND GENETIC TEST RESULTS

Otto Meletzke, JD

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MODERATOR: Most of the people in this room know Otto Meletzke very well, because he appears on every committee that the ACLI has ever invented. He comes to tell the story of what you can't do because it's against the law. The first meeting of the genetic testing committee that I went to was in Banff about three years ago. The first order of business of the meeting was for Otto to tell us that we couldn't talk about anything about genetics and how we would underwrite it. Today he will talk to us about confidentiality. (applause)

MR. OTTO MELETZKE: As an overview of our topic, I'll give you a brief sketch of the confidentiality/genetic issue and provide you with some background. That's roughly a third of my presentation. I'll then describe our recommendations for a voluntary confidentiality program, and suggest some specific practical implementation strategies for your companies. Finally, I'll point out some of the issues we ought to anticipate if we have confidentiality regulation in the future. These last two points will be the balance of my talk this afternoon. If we have time, I can attempt to answer some questions.

The Issue Now and in the Future

Basically speaking, the concerns about unauthorized access to genetic testing information — much like access to any other sensitive information — are fairly simple to describe and anticipate. They center mostly around employment and insurance areas, and involve unjustified “discrimination,” based on the sensitive information. Life insurance has not been high in the “hit” list, but one of the most dramatic issues has been: how can you keep health insurance underwriting and claims information out of the hands of other insurers, present or future employers, creditors, or others who could use the information adversely? Now, obviously, underwriting information in the self-insured and group area is non-existent; but claims information does exist, and there is not at the present time any legal requirement that regulates the flow of information back and forth in the self-insured group, or ASO market. This problem exists today, and is not unique to genetic information.

With the potential during the Clinton Administration of universal access to medical cost reimbursement, much of this will change, and more about this later. What may be left in the health insurance field could be very little. But what is most important for us here today is that life insurance companies — if down the line genetic tests become a viable, reliable tool to detect adverse selection — or even if companies do not test — must be subjected to some regimen of confidentiality standards for life and disability insurance. So that is the problem. Now, what do we do about it?

Background

All of you have been provided with some basic materials I want to mention:

- The first is a paper I prepared for publication in the Seminar proceedings, entitled Confidentiality of Medical Information from the Perspective of the Life Insurance Business; this paper highlights the historical aspects of confidentiality and talks about the practical problems and commitments from a company standpoint.

It was presented to a high-level HHS Task Force, and it may be reviewed in the future by the staff newcomers in the Clinton Administration.

- The second publication is the report of the ACLI Privacy Subcommittee to the CEO Task Force on Genetic Testing, which — even though its been out for a couple of years — recently got some very encouraging press in a publication called Privacy Times, where we were, in effect, congratulated for taking the lead in recommending a voluntary confidentiality program. Our report has also been given wide distribution to federal policy-makers. It's easy reading; many of you have seen it before, and this might be a good piece of reading material on your way home from the Seminar.

Meanwhile, let me give you a quick summary of what we had to say in this report.

The ACLI Privacy Subcommittee was given the job of making appropriate recommendations whether the potential use, if any, of genetic test results by insurers will require special confidentiality concerns, and if so, what response should be forthcoming. We reviewed the privacy and confidentiality experience over the last several decades, including the Federal Fair Credit Reporting Act in the late 60's, the confidentiality principles of the
Federal Drug and Alcohol Abuse legislation enacted during the 70's, the Privacy Commission's seventeen insurance recommendations, the Federal Insurance Fair Information Practice proposals of the Carter era, and the NAIC Model Privacy Act. We also looked at AIDS confidentiality issues at state and federal levels, and particularly, the federal confidentiality AIDS proposal advanced by Congressman Henry Waxman of California in the late 80's. From all of this, we drew a distinction that is quite important and fundamental to our topic: that is, the difference between fair information practice principles on the one hand, and confidentiality issues on the other.

Understanding of this distinction is a must!

Fair information practices are really the sort of "up front" disclosure about how you are going to go about gathering certain information, how that information is to be collected, how it is to be stored, how the individual can access it, and finally, how the individual may correct any incorrect information in order to reverse or modify an adverse decision, e.g., declination or rating.

All of the laws with which life and health insurance companies are familiar in this area — basically the NAIC Model Privacy Act — contain little in the confidentiality area, which, simply put, is a pledge not to redisclose information disclosed to the company without the individual's express consent. Section 13 of the NAIC Model Act presumes to deal with confidentiality, but really does not — basically because the issue was not of the significance it has been since the AIDS outbreak. Remember, this law was drafted in the late 70's.

This distinction permeates our whole dialogue on confidentiality. Basically, it says that I get this information in confidence, and I don't redisclose it to a third party without the permission of the individual who gave me the information in the first place.

Now that's the basic premise, and, of course, there must be exceptions for what I would call "routine" general business redisclosures that you can describe to the individual "up front" when you take the application. The best example that comes to mind is "let's describe reinsurers in a generic way, and not necessarily talk about Lincoln National."

Or, let's talk about redisclosures necessary in order to discover fraud perpetrated by the individual, where obviously you won't want to go back to that individual for permission — which will most certainly be denied. There are several other generic exceptions, but these are the basics.

So that's how the Privacy Subcommittee approached the whole topic, starting with the premise that the individual should have some control over redisclosure of information to third parties.

Mind you, we are not talking here about initial medical disclosures by the applicant to your company in the first place. That's an entirely different issue, and its not confidentiality. Instead, this issue is the public policy decision to prohibit the gathering of certain information for insurance or other purposes. Example, race, information gathered illegally (pretext interviews), etc. Query: will we be permitted to inquire about genetic information? Frankly, I can't predict this one, but please understand that this is not a confidentiality issue.

I would also highlight the fact that, as the Subcommittee looked at this whole topic, we discovered that the life and health insurance business has a long and reputable tradition of confidentiality, stemming from the earliest days of the business, and basically related to the relationship between the insurance agent and the client. My paper highlights this point. The other point I would make is that we looked at different methods of promoting confidentiality standards. We looked at voluntary programs; we looked at federal law, such as the Federal Alcohol and Drug Abuse regulations in 42 CFR Part 2; we looked at the state's role in promoting the NAIC Model Privacy Act; we looked at state AIDS confidentiality laws; and finally, we looked at the federal Waxman AIDS confidentiality proposal.

We concluded that, taking everything into account, the confidentiality issue was not susceptible to state-by-state solution; the state track record with the NAIC Model bill is, frankly, unimpressive, with only about 14 jurisdictions in nearly 15 years. We also looked at the way insurance AIDS proposals at the state level were handled, and concluded that it's a patchwork of conflicting and not very well known statutes. And, we looked carefully at the Federal Alcohol and Drug Abuse regulations, which are probably the strictest confidentiality standards extant.

But, though these are very strict regulations, they are not well known, even in the medical community at large. And those of you in the audience, I would surmise, are probably not that familiar with the exact scope of these regulations, and what is more, I'm not sure whether 42 CFR Part 2 is really being enforced, much less understood!

There is some interesting litigation that I could go into after our session that took place some years ago that cost one of our member companies a considerable amount
of money, but that’s the only problem I am aware of, except for the mechanical nuisance of dealing with the stamped forms that occasionally come back to underwriters.

Taking all of this into account, I was convinced, as were all of the folks that did the policy work on this project, that the real dedication and commitment to the privacy ethic over the last 20 years has come not as a result of law or regulation, but as a result of a commitment by a number of life insurance companies that this was simply good business and that, like privacy, our confidentiality standards should be very high. From this experience, it seemed to us appropriate to have the initiative in the genetic testing and other medically sensitive areas come by way of a voluntary program that hopefully would be adopted by a significant number of companies in their own best interests.

This may sound like the easy way out; it is most certainly not!

After 33 years in this city, I think I have a pretty thorough feel for when legislation works, and when it is appropriate. We’re nowhere close on this issue; not yet!

OK, that’s the background of the whole thing. We needed a program that was simple, understandable, flexible, and somewhat uniform, although companies obviously have to take different approaches for different types of business and so on.

Voluntary Principles

Without further ado, let me sketch out exactly what our voluntary program involves. It is very simple. There are only four principles:

- Principle One simply says that a commitment should be made to applicants and insureds that, with the exception of several defined circumstances, the redisclosure of genetic test information will be made to third parties only with the written consent or authorization of the individual or his or her representative. It was our thinking that this consent could be obtained at the time the application was taken, and would remain valid throughout the lifetime of the policy. It should be specific where this is possible (in other words, spell out the MIB) and generic where otherwise necessary, e.g., reinsurers, coinsurers, contractors, etc. The exceptions to this principle — in other words, redisclosure without written consent or authorization — should be limited to roughly the following circumstances: (1) in limited non-discretionary situations pursuant to state or federal law (in other words, where required by insurance regulators, law enforcement authorities, etc.); (2) where an adversarial relationship exists (or could exist) between the individual and the insurer, such as in the area if disputed claims and where fraud detection and deterrent are involved; (3) in extraordinary situations that you can’t anticipate up front, such as in the sale or merger of the company; and (4) for research or statistical purposes, such as actuarial or medical studies.

Principle One also says that, except in the situations I just outlined, insurers should, where the redisclosure was recorded, inform the individual of this fact upon his or her request. In other words, somebody writes in and says "Have you ever made a redisclosure to a reinsurer?" You should say, "Yes, we have, to X company on Y date." Maybe you also want to say why.

- Principle Two says that all permissible redisclosures should contain only such information reasonably necessary for the recipient to perform its function and the recipient, in turn, should generally be prohibited from making further disclosures without the specific consent of the individual. Here is an illustration: suppose you’ve got a situation where a claim is under investigation and you ship the file to an outside firm for review. That firm should not have anybody other than the people assigned to the case looking at that file, and clearly should not make a further disclosure without the permission of the individual (hopefully through the company). Now, in this case where we don’t have fraud or a contested situation, it’s just a routine kind of thing. So there wouldn’t be a "redisclosure" exception to the first Principle in the adversarial or fraud area. You would have covered the redisclosure to the contract firm "up front" in a generic way.

- Principle Three says that internal operating policies and procedures should be adopted to restrict authorized access to all genetic testing information to only those who are aware of internal confidentiality policies and also have a legitimate reason to have access to policyholder information. In preparation for the paper I recently wrote, I spent several days at a major member company of ours, and I was enormously impressed with the commitment of top management and underwriting and claims personnel to these very kinds of confidentiality policies. It was clear that we weren’t talking about genetic testing, we were simply talking about medical information, and nobody had access to any of that information unless they clearly had a legitimate reason, and had made a written commitment to maintain confidentiality. So this is not
a big deal. This is something all or most of you here are doing, hopefully, in a formal way.

- And finally, Principle Four, which simply says that companies ought to publicize their confidentiality policies and restrictions they impose on the redisclosure of genetic testing information. The reasons for this principle are fairly obvious: good business publicity.

I could go on and on about how we came down to four principles instead of six, or ten. But this is of no moment, and since these are recommendations for voluntary implementation, I would be pleased to see companies develop whatever they need. But I think four really does it, basically, and they meet the definition we set down for simplicity.

One point I should make that was debated at the CEO Task Force level, and that is whether we ought to cover genetic testing information only, or extend the principles to other sensitive medical information, such as HIV information and so forth. As it came out we were narrow, and said that's where the focus ought to be — on genetic testing information. But there is a clear implication in the thinking and background and the thrust of this thing that it's going to make sense if you set up a program for this type of information, it probably ought to include other types of sensitive medical information so you don't have two or three different standards for this information, all of which is sensitive to the individual.

Let me also mention some important background information. Earlier, I referred to the experience we had at the federal level several years ago with legislation dealing with AIDS and confidentiality, which was sponsored by Congressman Waxman of California. The legislation came within a blink of enactment, but the "give and take" legislative experience for us was extremely instructive, because it pointed out that the life and health insurance business could make certain accommodations for sensitive medical information and, in effect, pledge not to redisclose sensitive HIV information without the permission of the individual, except in several very specifically-defined areas; namely, where fraud was involved, where information had to be provided, for example, to insurance regulatory authorities, and so forth.

What with that experience with the Waxman legislation and with the work of our Privacy Subcommittee focused on genetic testing information, I am convinced that the voluntary route is the best way to go, not only because it makes good sense from a company and industry standpoint, but it may well prepare us at some point down the road for national standards that may be imposed by legislation.

Practical Strategies for Implementation and Why

What are the practical strategies suggested here? My zeal about this topic involves a simple premise — you are the folks who can make something happen in your company to deal with one of the most pressing ethical dilemmas we will face in our careers. On the one hand, we have been tagged with the perception of evil motivations on our part by our critics; on the other hand, we have a track record of familiarity with medical sensitivity second to no other business in the world.

It's now a little bit more complicated than when we wrote the confidentiality report for the Privacy Subcommittee. As I mentioned at the outset, we now have what appears to be a major part of the health insurance business endorsing universal access to medical expense reimbursement. Sophisticated medical underwriting, to the extent it existed at all in the small group market, may well be an historic footnote; the individual health insurance market is clearly diminished; and we're left with life insurance and disability income — and even here, there is no consensus that any widespread genetic testing will (1) be ethically rationalized; (2) cost-effective; or (3) acceptable as a public policy matter. But, like it or not, the issue of "whether testing" may have nothing to do with confidentiality. Taking an extreme prospect, even if testing is prohibited in underwriting, what do you do with genetically-related claims information? So, like it or not, we've got to get off the spot on confidentiality standards for genetic testing information, as well as other medically-sensitive information. In other words, even if we don't use it, we may get it anyway. So, we have to deal with the issue. This point is discussed at some length in the Privacy Subcommittee report, and I recommend it to you.

So, I repeat, what's the problem? The problem is that life insurance companies — which are the major players in the health care debate — must set the tone, and establish the beat in the confidentiality area. We can't afford to wait for the other guy to move!

Let's now talk about practical stuff you can take home with you to implement a program. What do you do? The first thing you do, it seems to me, is draft a memorandum to your CEO and recommend the establishment of a task force made up of, perhaps, medical, underwriting, legal, marketing, field relations, and other disciplines. This I will leave to you!
You’ve got to get motivated about the subject; you folks are the leaders in this area, and don’t look for help initially from your lawyers and government relations people; they are trained to be conservative and protective of the status quo. What we need here is a medical, ethical, public relations effort. And the beauty is that it costs virtually nothing!

At the first meeting of your group, you’ve got to set a goal of establishing policy for the company as a whole. Write some draft memos to affected departments (underwriting, claims, field force, etc.), and put some punch into them — don’t be timid. Take our report and use it; be direct, but also flexible; let difficult medically-sensitive decisions be made by medical professionals, and don’t get bogged down in procedural details. Be firm and clear (I suggest avoiding hypertechnical medical distinctions). And get it eventually to the field force — they will need to be re-acclimated to a new era; their confidentiality commitment must be both reaffirmed and redefined. And get some positive publicity out of this effort. In spite of the fear of the unknown, this is good business. Believe me! Let me say this — an old adage — the best defense is a good offense.

I don’t think this is something you can procrastinate about. We will have more state legislation in the testing prohibition area, but these are basically politically-motivated nuisances that are not reflective of national public health policy consensus. This is not truly a state-by-state issue, as I’ve said. Genetic disabilities are not a regional underwriting phenomena like coal mining, or maybe bungie-jumping in Florida! And, believe me, when the final Genome Project recommendations are made, they won’t commend Wisconsin or Florida for taking the lead; they will call for a national public health commitment for all Americans.

In any event, this type of state legislation will probably focus on testing, more than on confidentiality, and it will probably continue to focus on the health, not the life, side of the business.

If you get a program in place, you will be ready for the basics; your professionals will be ready, and you will have familiarized your people with a "compliance or commitment mentality." Whether we ever see genetic testing information in medical underwriting or claims, we, as an industry will have acted responsibly as we have for the last 20 years in the fair information practices area.

There is an analogy here that seems to me very appropriate: a decade ago, responsible corporate America began to appreciate the difficulties experienced by individuals with physical and other disabilities. They began to accommodate both structural and other barriers faced by disabled people. They anticipated the Americans with Disabilities Act!

We should take a page from this. The time is now. Let’s anticipate negotiations on this issue on a positive note. I can’t do more here than expose the problem; I wish I could sit down with each of you and design a program, but I can’t. If you take anything home with you from this talk, I hope it’s clear that this is your problem, your company’s problem, and most importantly, your potential customer’s concern.

So, you put a voluntary program in place. And, later on, federal legislation comes about. What are some of the practical, political possibilities here in the confidentiality area?

As I mentioned, with the prospect of federally-guaranteed access to medical care expense reimbursement for all of the citizenry in the near term, the insurance genetic testing issue becomes more of an abstraction then, say, two or three months ago, and the genetic testing confidentiality debate takes on new dimensions.

On the assumption that, in the long run, health insurance medical testing and underwriting will be eliminated at the base level (a radical idea maybe, but one that has been endorsed by the populous and, indeed, the HIAA Board), legislative and public policy concerns over genetic testing should decelerate. I don’t think public policy makers truly care that much about the abstract potential of genetic testing by life insurers (for adverse selection) for large face amount policies. They will understand that this is an "arms length" business transaction that puts us "on the hook" after the contestable period, for a lifetime. Less focus on health should help our case in life and disability. So, (1) life insurance companies (which will be the major players in new health care policy) must take the lead as they have in the fair information (privacy) practices area in establishing high medical confidentiality standards; (2) the voluntary confidentiality principles we developed for life and health insurers should become a priority (at a minimum for the education of company personnel).

In any event, we are left with at least two confidentiality issues.

First, to preserve the prerogative of flexibility and other positive aspects of voluntary standards for genetic testing, and other sensitive medical information in the life insurance and disability income business, and second, to seize the moment to exercise leadership and influ-
To lead you in this direction, let’s look at how “progressive” we have become over the last three decades. We first had an assault on “moral hazard” underwriting almost 25 years ago with the Federal Fair Credit Reporting Act. But this has been a “piece of cake” for our industry; among other things, because sophisticated, cost-effective, medical underwriting has dramatically reduced the protective value of third-party interview inspections. Second, we had the extensive laws and regulations in the drug and alcohol abuse area that, frankly, nobody knew about in our business when they came out, and they really haven’t been that painful for us either. Third, we had the Privacy Protection Study Commission, with 17 detailed insurance recommendations. This was kind of a “no-brainer.” It was good stuff; the NAIC picked it up, and the rest is history. We now have 14 jurisdictions with the Model Act — not a lot, but better than nothing. And, a number of nationwide companies voluntarily comply in all jurisdictions. But that’s in the informational privacy area (Fair Information Practices), not the confidentiality area. Fourth, we had AIDS, and here is where we really begin to face the confidentiality issue, but not in an anticipatory stance as we now face the genetics issue. Fifth, we had the CEO Task Force reviewing all of this background, including the specific confidentiality recommendations of the Subcommittee report. We suggested responsibility, and that’s what it’s all about.

We’re now back to square one. Our report has been out for a couple of years, and we need to pay more attention to it. We’ve had state legislation on genetic testing, but not directly affecting the confidentiality issue.

But I think we can draw on our superior experience over the years with HIV and other sensitive medical information in the underwriting and claims area, and anticipate the genetic issue — even though there are no companies, to my knowledge, utilizing these tests.

The other aspect here is that the employer community must be brought up to speed as is the case for every third party that insurance companies and their agents and brokers deal with.

Is this an insurmountable problem? I think not. Our effort must depend on (a) simplicity, (b) understandability, (c) commitment from all of you here, medical directors, ethicists, lawyers, company and government relations people, (d) publicity, and understanding from our adversaries — many of whom are here in the audience.

In the long run, if not the short, it will succeed as a matter of professional commitment.

I suggest that in the genetic testing area, we’ve got to distinguish sensitivity concerns in the abstract, from perceived concerns about unjust discrimination. We have to look closely at claims information security on the health side, even if employers in the future may not legally be able to use adverse “disability-type” medical claims or other information against an individual for employment purposes. (My theory here is that the Americans with Disability Act may possibly be interpreted over the next few years to close this down.)

We have a clear dilemma masquerading as a challenge, for those of you willing to take it: sophisticated medical underwriting is at its apex — including the potential of genetic testing for adverse selection. But the public at large — policy-makers and lawmakers alike — is probably not going to weigh in on our side. Health insurance, no! Maybe, life and disability — if we demonstrate “responsibility,” and I think that’s the key.

Well-run companies will probably approach this issue with caution. What to do has got to be your choice. I would counsel a cautious, but progressive approach, taking some constructive steps toward building a defensible confidentiality policy. It will pay dividends in the years to come.

Thank you very much for your attention, and feel free to pick up the phone any time and give me a call about this topic. I’d like to help. I believe we have major
ethical, medical, customer-relations problem at our doorsteps. What we do with it is now, for the moment, in our control. If we avoid it, the venue shifts, we lose ground; we lose control; we lose credibility.

And credibility is what this business is all about!

DR. SANDY LOWDEN, Crown Life: It's the broker who gets the information when he fills out an application form. He sticks a copy of the APS in his own file and shops it around to four or five other insurance companies. I think this is the place that we have the biggest problem in maintaining confidentiality.

MR. MELETZKE: I certainly agree it's a very important problem, and it's very difficult to handle. It seems to me you've got to set up some written policies. The broker is a little more difficult. Where you have a general agent situation, there could be liability to the general agent. Maybe you need to scare these folks a little bit. This is a problem that has more sensitivity than it used to.

DR. THORNE SPARKMAN, Covenant Life: Can I ask what are the terms under which data banks run by researchers are maintained? Under what circumstances can information from those be obtained by the patient or his family for instance?

DR. MICHAEL KABACK: I think there are a number of different ways. Many of them tend to be ad hoc and not really formalized in any fashion, but for the most part there's been a great concern. As the potential for developing data banks became a reality, there was a lot of discussion amongst the genetics professionals about the concerns that you've touched on vis-a-vis confidentiality. For that reason, at least to my knowledge, those banks of data have been established with great caution. There's no name or identification other than coding systems, and access is extremely limited. In fact, I think there's no access other than the investigator himself.

DR. REILLY: It may be that the genetics and research community will learn from the insurance industry, actually. One of the things that is lurking on the horizon for us is the development of a rather large DNA data banks, being developed from a multiplicity of sources. First of all, the military is now collecting blood samples from all new recruits to aid in DNA-based identification should a tragedy occur, such as the missile in Iraq. Two, many states now have laws that provide for the compilation of DNA-based felon data banks to deal with the problem of recidivism, particularly in rape. When a convicted sex offender is discharged or paroled, on the way out the door he leaves a blood sample, which is then reduced to a DNA profile. Three, many researchers around the country have small data banks related to disease. They're doing a linkage analysis, or whatever. Four, and this is a particularly interesting one, commercial entities are now offering DNA data banking as a service. You've a family history of colon cancer. There's no genetic basis for it that we know, but two or three relatives died of it. Why not have your grandparents store their DNA in anticipation of the time that we can offer a linkage test to someone else. No state, to my knowledge has developed a set of rules about regulating the commercial practice of DNA banking and DNA data banking. I use the two terms because one refers to saving an actual biological sample and the other refers to saving some digitalized record of it, perhaps. I think we're going to see a lot more of this collection and storage of information. There will be a lot of interesting questions about who may talk to whom about it. At the research level it's largely been answered through an institutional review board (IRB). Whenever someone's collecting sensitive data we say, "How is it going to be stored?" And the researcher has to say, "It's anonymous," or "It's being kept in a locked drawer," or whatever it might be.

DR. MOSELEY: I was pleased to hear that there haven't been many complaints about violations of confidentiality. That's really gratifying. I'm not confident that indicates there haven't been some problems there. I think that consumers often may not know that confidential information has been released. Additionally, they may not know to whom to complain, or that they even can complain. So, I wouldn't be so totally reassured I don't think. That doesn't mean there are no problems.

MR. MELETZKE: I'd like to comment on that. I know what you're saying, and I had the same level of suspicion myself, frankly. The vast majority of our applicants are issued standard, with only a small percentage, three or four, with a rating, something like that. Declination rates are quite small. So there really isn't any incentive for anybody to be upset about anything if they've gotten the coverage that they wanted. What drives the issue is something that has happened to this person. They don't get the insurance, or they don't get it at the price they applied for. So they say, "Wait a minute. Why did I get declined?" Under the Fair Credit Reporting Act and the NAIC Model law you have the right to know the reasons for the underwriting action. But people are not going to complain in the abstract about some redisclosure to an unknown reinsurer if they got the policy. That may not sell you from an ethical or philosophical standpoint, but I think it's sort of the way it works. I think you could cure that somewhat, because you would publicize the standards.
DR. A.C. FAVORS, General American Life: When an application comes into the insurance company it changes hands many times through different sections. I wonder if you might address the "in-house" confidentiality. And the other thing, to my amazement, I recognize names of people, even patients, that I’ve seen in some other state. Obviously, as a physician, I’m well aware of confidentiality, but to me there are many potential sites for inadvertent leaks of information.

MR. MELETZKE: I think the only comment I could make is, you’ve got to have a strict but flexible policy with a commitment right from the top. In a company I visited, one of our biggest, all of the people have to sign a pledge that, in effect, if they violate they’re out the door. You have to sort of build the zeal some way. You know, you can’t build a perfect mouse trap, and mistakes do happen. You need the commitment from the top and that should work. (applause)

_Suggested Reading_

Addendum to Paper by Otto Meletzke

CONFIDENTIALITY OF MEDICAL INFORMATION FROM THE PERSPECTIVE OF THE LIFE INSURANCE BUSINESS

I. Purpose and Summary

A. Purpose of the Paper

The purpose of this paper is to provide an overview of the confidentiality policies and practices of life insurance companies, and in particular, in maintaining the confidentiality of medical information gathered and utilized in the underwriting and claims processes. It is intentionally limited to policies and practices relating to individual life insurance policies, although many basic principles discussed are applicable to the health insurance business as well. There are, however, important differences, particularly with respect to group health insurance and the underlying employment relationship involved.  

B. Summary of Observations and Conclusions

The underlying theme of the paper is the important historical tradition of the life insurance business in insisting on confidentiality as a basis of the personal insurance relationship. It also reviews the historical developments of more formalized fair information practices during the 60's and 70's, and the AIDS confidentiality concerns of the 1980's. It discusses more recent developments, including a study of genetic testing issues undertaken by the life and health insurance business several years ago. Included is a review of the voluntary confidentiality initiatives recommended in that study for the treatment of genetic testing and other sensitive medical information that may find its way to underwriting and claims operations. An appendix to the paper answers specific medical confidentiality questions from the standpoint of a typical large life insurance company.

From this discussion, it is clear that confidentiality of medical information has been a mainstay of the life insurance business for many years. This has in large part been due to the tradition of confidentiality between the agent and the applicant, this same commitment among the various specialized disciplines in the home office setting, e.g., underwriting and claims, and because of the influence of medical directors and other medical professionals who have brought to the business the ethical disciplines of the medical profession itself. At the same time, it is also clear that the public policy debates and developments over the last 20 years have heightened the sensitivity of the business in this area, so that more formal programs and policies with respect to medical confidentiality have been put in place in recent years, and more can be expected in the future. The paper concludes that the flexibility available through voluntary adherence to medical confidentiality policies currently serves the public interest, applicants and policyholders alike with a high degree of sensitivity and responsibility. It further suggests that this mechanism will serve the business and the public as well in future years.

II. Confidentiality: A Fundamental Aspect of the Personal Insurance Relationship

A. Historical Background and Tradition - The Nature of the Relationship

Historically, the very nature of the life insurance business has involved personal and confidential relationships. The business has, accordingly, been dedicated to the proposition that dealings between companies and agents with prospective insureds that had financial and medical sensitivity implications had to be on a very confidential basis. This proposition applies also to the collection, use, maintenance, and dissemination of medical record information. An appendix to the paper answers specific medical confidentiality questions from the standpoint of a typical large life insurance company.

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II. Confidentiality: A Fundamental Aspect of the Personal Insurance Relationship

A. Historical Background and Tradition - The Nature of the Relationship

Historically, the very nature of the life insurance business has involved personal and confidential relationships. The business has, accordingly, been dedicated to the proposition that dealings between companies and agents with prospective insureds that had financial and medical sensitivity implications had to be on a very confidential basis. This proposition applies also to the collection, use, maintenance, and dissemination of medical record information. An appendix to the paper answers specific medical confidentiality questions from the standpoint of a typical large life insurance company.

From this discussion, it is clear that confidentiality of medical information has been a mainstay of the life insurance business for many years. This has in large part been due to the tradition of confidentiality between the agent and the applicant, this same commitment among the various specialized disciplines in the home office setting, e.g., underwriting and claims, and because of the influence of medical directors and other medical professionals who have brought to the business the ethical disciplines of the medical profession itself. At the same time, it is also clear that the public policy debates and developments over the last 20 years have heightened the sensitivity of the business in this area, so that more formal programs and policies with respect to medical confidentiality have been put in place in recent years, and more can be expected in the future. The paper concludes that the flexibility available through voluntary adherence to medical confidentiality policies currently serves the public interest, applicants and policyholders alike with a high degree of sensitivity and responsibility. It further suggests that this mechanism will serve the business and the public as well in future years.

1 "Medical information" is here used in the broad sense, to include information concerning medical status and condition supplied by an individual to an insurer, as well as medical record information supplied by third parties pursuant to authorization by the individual.

2 The scope of this paper does not extend to a discussion of group insurance, principally because this insurance coverage is not individually underwritten. However, sources such as the Health Insurance Association of America should be consulted with respect to group health insurance as it relates to claims and the confidentiality of medical information, and the employer (policyholder)-employee relationship.
ance companies provide personal lines of insurance coverage.

B. Personal Insurance

Personal lines of insurance are designed to protect against premature death and disability, and, unlike property and casualty coverages, depend on the provision of unique personal information by applicants, including medical information. In the case of life insurance, companies are obviously concerned about health status and projections of longevity. Medical information about the individual is extremely important, and in most cases the flow of this information to insurers is central to underwriting the particular individual risk. Historically, this has never been a problem for the applicant seeking life insurance protection. But insurance companies carrying out their responsibilities must have the confidence not only of the applicant, but that of medical professionals -- as well as the public and policy makers -- that they will handle medical information in an appropriate way. For these reasons, medical information has always been held in confidence and treated with respect and discretion.

In evaluating new life insurance risks, underwriters and medical directors must also consider the interests of existing policyholders. Life insurance involves long-term, lifetime commitments. The lifetime duration and incontestability features of the whole life insurance contract reinforce the need to require a great deal of personal information in order to fairly evaluate the risk, price the product, and adequately protect existing policyholders. After all, absent fraud, once the two-year contestable period in these contracts has run, the contract cannot be terminated by the company, except for failure to pay premiums, which are fixed for the life of the contract. This, of course, is not the case in property and casualty insurance, which is generally renewable on a term basis at the option of the company, and which allows for premium increases or coverage changes.

C. Familiarity with the Confidentiality of Medical Records

The familiarity with the confidentiality principle as it relates to medical information stems not from medical confidentiality laws, but principally from two important disciplines in the life insurance business: underwriting and claims. The underwriting discipline is charged with making appropriate risk classification so as to provide equity to existing policyholders as well as to the new applicant. In the underwriting process, medical information can play a most significant part, and it is important to understand that this information may come from several principal sources. The first source is information provided by the applicant, usually to a life insurance agent, about the state of his or her health. Any pertinent family medical history is also usually requested, in order to provide a basis for possible further inquiry by the company's underwriters. Frequently, depending on the amount of insurance applied for and other considerations, an attending physician's statement is secured by the company to confirm or develop medical information of significance. Life insurance companies may also order independent medical tests, with the approval of the individual, which are usually processed by outside clinical laboratories. Depending on the risk, and particularly in large face amount policies, the number and sophistication of medical tests and procedures will increase. For example, it is not uncommon for medical directors to order stress tests in large face amount cases, to detect possible cardiovascular risks. In addition, today, because of the AIDS crisis, all life insurance companies use screening tests for the presence of the HIV antibody.

In other situations, underwriters and medical directors may also request -- with authorization of the individual -- hospital records and other medical information from third-party providers that, again, is deemed to be pertinent in classifying the risk and in placing the insurance in force. As the underwriting process continues, the confidentiality of this information is in all cases secured within the underwriting department and made available only to those company personnel who have a legitimate business reason to have access to the data. Similar security precautions are involved where claims situations are involved.

In the claims setting, life insurance companies are generally dealing with routine causes of death that will not involve extensive investigation. Cause of death information, nonetheless, is handled with the same degree of sensitivity as is the information in the underwriting stage of that particular policy. Information is gathered from third parties only with appropriate authorization and with the understanding that any such third party disclosures are a necessary part of the insurance transaction, e.g., settlement of the death claim. In the relatively small number of cases involving contestability of claims, third-party disclosures, again, are made only in connection with the contestability issue, and it is understood that this information is not to be disclosed further.

\footnote{Most states' medical confidentiality laws are general in nature and are not specifically directed at the activities of insurers, see Nicholas D. Latrenta, "Privacy and Fair Information Practices Principles in the Life Insurance Business", American Council of Life Insurance Legal Section Proceedings 180-183 (1990).}
Another important point should be made: that is, the importance of medical professionals in life insurance companies and their commitment to the confidentiality ethic. Medical professionals in the life insurance business have always played a very important role, particularly in the underwriting process. Their expertise with respect to medical impairments has always been a requirement in the business, and the presence of medical directors in the life insurance business has made for a firm commitment to the medical-ethical aspects of confidentiality and medical information. These same medical professionals are also thoroughly familiar with the confidentiality implications of claims administration, and the Medical Information Bureau, whose services are extremely important to medical underwriting. And, with the dramatic advances in medical underwriting over the last 20 years, the importance of these medical professionals in the day-to-day operations of life insurance companies has become considerable. With the advent of emerging medical technology, e.g., genetic testing, tumor marker testing, etc., the commitment of these medical professionals to the confidentiality ethic will be even more important. In fact, in life insurance medical circles today, it is imperative, as witnessed by the attention given to this important issue in life insurance medical associations and journals.

III. "Privacy" — Fair Information Practices
Developments in the Life Insurance Business

In order to develop a perspective on "confidentiality" in the life insurance business, it is necessary to draw a contrast between traditional concepts of "confidentiality," on the one hand, and "privacy," on the other.

What is meant by confidentiality in the context of medical information is quite simple, and arises with a commitment of nondisclosure (or no redisclosure) of the circumscribed information (test results or information associated with or inferred from such results) to any parties other than the information originator and the initial recipient. Usually, compliance is easily evaluated since any breach of this pledge is, accordingly, a "literal" breach of confidentiality. The corollary to this basic pledge, in most confidentiality settings, is disclosure to third parties only with the explicit consent and authorization of the individual involved. Under even the strictest of confidentiality programs, however, certain types of limited disclosures are permitted without the explicit authorization of the individual.

The concept of "privacy" was defined more or less comprehensively for the insurance business in 1977 by the Privacy Protection Study Commission, and was interpreted to include fair information practices that govern the collection, maintenance and use, as well as the disclosure, of personal (including medical) information. These practices also embraced, among others, notification and correction procedures with respect to such information.

A. Influence of the Fair Credit Reporting Act On Fair Information Practices

Until the 1960's, when the use of reports prepared by outside firms for underwriting came under Congressional scrutiny, the business rarely experienced any major criticism of its privacy or confidentiality standards. However, after almost five years of Congressional inquiry concerning the information-reporting industry and the use by businesses of reports it generated, the federal Fair Credit Reporting Act became effective on April 25, 1971. The FCRA places specific requirements on insurance companies utilizing such reports for underwriting purposes. These are essentially two-fold -- involving a "prenotice" under Section 606 of the Act, and a "post notice" under Section 615 of the Act. These requirements changed in some respects the way life insurance companies handled the ordering of reports in connection with the underwriting of new business. Thus, for over 20 years, insurers have included a prenotification with applications advising the applicant of the possibility that such a report might be procured, and the applicant's rights under the Act, in the event that a report was in fact obtained. In addition, the FCRA pro-

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4 For a discussion of the privacy implications of MIB, see Latrenta, Id. at 202-209.
6 There are limited legitimate exceptions that must be made, in defined circumstances, such as disclosures made pursuant to legal or regulatory process, or others of necessity, e.g., when the information originator is deceased. See also Latrenta, supra note 3, at 249-257.
7 Id.
8 For a full discussion of this point, see Latrenta, supra note 3, at 212-216.
10 Id. at 51681m(a)-(b), and 51681g.
vides that any user of a report who bases an adverse action wholly or partly on information contained in such report must advise the individual against whom such adverse action has been taken and supply the name and address of the firm making the report. The concerns of those supporting enactment of the FCRA centered around third-party assessments of individuals’ financial and other characteristics, rather than the utilization of medical and other underwriting information. Nonetheless, the focus of the FCRA, i.e., the ability of individuals to correct incorrect information, made sense and positioned the life insurance business in a positive stance as it anticipated the next developments of the mid-Seventies when the Privacy Protection Study Commission undertook an in-depth study of fair information practices in the industry.12

B. The Privacy Protection Study Commission

The concerns voiced about computers and privacy in Congressional hearings launched in the 1960s set the stage for a variety of privacy initiatives. At about the same time, questions were raised about life insurance information-gathering techniques. The criticisms leveled at the life insurance business in this context concerned the subjectivity of the information that was being collected, and the inability of individuals to verify or correct misinformation that may have led to adverse underwriting decisions. "Watergate" also set the stage for what followed.

As part of the Privacy Act of 1974, there was created a seven-member Privacy Protection Study Commission. The Commission’s principal responsibility was to make recommendations with respect to privacy laws or regulations concerning the private sector.

Because of the importance of potential privacy issues to the life and health insurance business, in 1974, the American Life Insurance Association, a predecessor of the American Council of Life Insurance (ACLI), appointed a Subcommittee on Privacy Legislation to assist in the consideration of legislative and related developments in this area. The Health Insurance Association of American (HIAA) followed suit. On May 19, 1976, a panel of seven insurance company officials testified before the Commission, covering virtually all facets of life and health insurance company operations, including marketing, underwriting, business administration, claims operations, group insurance and direct response insurance.14

On July 12, 1977, the Final Report of the Privacy Protection Study Commission was transmitted to the President and the Congress. The report was a massive undertaking, and covered in great detail the record-keeping and information-gathering practices of virtually all segments of society: credit grantors, depository institutions, employers, medical records professionals, insurers, educators and many others.

Chapter five of the Commission’s report was devoted solely to the “Insurance Relationship.” This chapter contained 17 specific recommendations aimed at giving individuals an opportunity to become more involved in the information-gathering process, to have some measure of control over information collected about them, the means by which it was collected, and how it was to be used or distributed after collection. As did the rationale of the Commission’s report generally, the insurance recommendations revolved around three public policy objectives: (1) to minimize intrusiveness; (2) to maximize fairness; and (3) to create a legitimate enforceable expectation of confidentiality.16

Following the issuance of the Commission’s report, the CLI Subcommittee on Privacy Legislation met on a number of occasions to develop the association’s policy concerning the recommendations. In addition, working groups from this subcommittee studied, in detail, the various recommendations and their implications, both from the standpoint of problems that might be anticipated with state or federal legislation concerning the insurance recommendations, and ancillary problems raised by them. These task forces continued their work throughout the balance of 1977 and into 1978, following policy deliberations by the association’s appropriate committees and governing boards.17

11 Id.
12 See Latrenta, supra note 3, at 188-196 for a detailed history and discussion of the life insurance business’s experiences with the Fair Credit Reporting Act.
14 See American Life Insurance Association, General Bulletin No. 2272 (June 1, 1976).
16 Id. at 155-222.
17 See Latrenta, supra note 3, at 217.
The ACLI was also active in bringing the privacy issue and the Commission’s recommendations to the attention of the National Association of Insurance Commissioners (NAIC), with the result that an NAIC Privacy Task Force was created to examine the recommendations, particularly those that called for state action.

The ACLI and the HIAA Boards were concerned about the PPSC’s original recommendations for a mixed scheme of implementation, through voluntary efforts, state, and federal involvement. Following consideration of several alternative approaches, the ACLI’s Board resolved the issue on a basis of primary implementation by the states. Similar action was taken by the Board of the HIAA. 18 This set the stage for the National Association of Insurance Commissioners’ Model Insurance Information and Privacy Protection Model Act ("NAIC Model Act").

C. Significance of the NAIC Model Act from the Personal Insurance Perspective

When the Privacy Commission began its work in the 70’s, the life insurance business was vigorous in its support of the final report and its 17 specific insurance recommendations. The business also worked very closely with state authorities on implementation of the recommendations, for the ultimate adoption and state implementation of the NAIC Model Act. 19 The NAIC Model Act was first adopted by the NAIC in 1979, but to date only 12 states have enacted it, with one additional state promulgating a regulation in the area. However, the fact remains that, even prior to the development of the NAIC Model Act, many insurers voluntarily adopted formal or informal information practices programs, based on the Privacy Commission’s recommendations. After the Act was adopted and began to be implemented by the states, more insurers adopted its principles on a nationwide basis. There is, as a result, considerable familiarity nationwide with the fair information practice principles contained in the NAIC Model Act.

The NAIC Model Act was, of course, based on the Privacy Commission’s insurance recommendations. While the Commission had favored a mixture of federal, state, and voluntary actions to implement its recommendations, the traditional regulatory method employed for the insurance business was the preferred choice of the regulators and the industry, i.e., state legislation. 20 The philosophy and objectives of the Act, in essence, amounted to a conclusion by the NAIC that the objectives of fairness in information practices deserved more attention, as did limiting intrusiveness and establishing a duty of confidentiality. 21 In the view of the NAIC, fairness in the information relationship was consistent with the Commission’s philosophy that privacy protection standards should govern the relationship rather than dictate a set of rules. This has, in fact, been borne out, since compliance with the model in the states where the Act has not been adopted has taken place by way of voluntary procedures to assure fairness in the information relationship.

The Act is, indeed, complex and contains many provisions that are, at first, difficult to understand. This is probably because the Act extends not only to all lines of insurance, but to support organizations and agents and brokers as well, and indeed, to entities such as Blue Cross-Blue Shield. However, looking at the Act from the life insurance perspective, its objectives and goals are quite simple and are only several in number: fairness in the information gathering process, including a notice to individuals about this process, communication of adverse underwriting decisions; the obligation not to re-disclose information to others without the consent of the individual, unless specifically addressed by exceptions in the Act; the ability to access most records, and to correct incorrect information; and the ability to pursue remedial action. Looked at from this standpoint, there is a simplicity to the Act that, indeed, lends itself to voluntary programs that deal with the real questions and issues in the life insurance process.

Medical record information is not singled out in the Act in terms of distinguishing it from other defined personal information. Thus, all of the rights and obligations specified under the Act apply, as well, to medical record information. Correction, amendment or deletion of recorded personal information under the Model Act extends to medical record information like any other information.

18 Id.
19 Id. at 221-263.
20 This discourse is established in Latrenta, supra. note 3, at 221-2.
21 Id.
The importance of the NAIC Model Act in the context of voluntary confidentiality initiatives should also be emphasized.\(^{22}\) The Act's fundamental principles form the basis for a confidentiality program, since they become the underpinnings for fair information practices that lead naturally to confidentiality standards.\(^{23}\) In other words, as has been pointed out previously, the life insurance business historically has held medical and other sensitive information in a confidential manner, disclosing only to those with the need to know within a company and those third parties with authorization from the individual himself or herself, and in certain other limited situations. But the preferred model for the 1990's and beyond is adherence not only to the confidentiality standards, but development of policies and programs for fair information practices that complement confidentiality standards.\(^{24}\)

D. Confidentiality of Drug and Alcohol Abuse Records (42 C.F.R. Part 2)

Perhaps the next development of significance to the life insurance business in the area of privacy and confidentiality was the promulgation of federal regulations dealing with drug and alcohol abuse programs, and their provision of significant privacy safeguards to individuals.\(^{25}\) Under these regulations generally, records pertaining to the identity, diagnosis, prognosis or treatment of patients maintained in drug or alcohol abuse prevention or treatment programs or activities, must be kept confidential. This is a long way of stating that disclosures of patient records involving these programs are essentially permitted only with the consent of the patient. Quite obviously, these regulations apply to life insurance companies where such companies in the underwriting or claims contexts seek to secure medical or medically-related information on individuals who have been treated in such programs. Their significance as a "marker" in the confidentiality arena cannot be understated, however, and many commentators have, indeed, looked to the principles in these regulations as fundamental confidentiality statements that could have applicability beyond alcohol and drug abuse information.

E. Importance of Individual Life Insurance Company Privacy Initiatives

From simply a practical standpoint, there is much to commend the furtherance of individual life insurance company privacy and confidentiality initiatives.\(^{26}\) Until the Privacy Commission study and the legislative initiatives that followed in the late 70's, all the confidentiality principles that have been such an important part of the life insurance business were carried out on a voluntary basis. Thus, the business is historically familiar with implementing such voluntary actions. Indeed, the point could be forcibly argued that the success of fair information practices in insurance programs over the last 15 years is largely attributable to company-sponsored voluntary efforts. Most of these initiatives were influenced not by the prospect of legislation, but by the Privacy Commission's substantive recommendations and their appeal to individual companies as a matter of good business practice.\(^{27}\)

It is also true that voluntary initiatives frequently draw criticism from those accustomed to elaborate rules, laws and regulations and those expecting enforceable standards of confidentiality, with equal expectations of readdress not necessarily focused on results but punitive remedies.\(^{28}\)

On balance, a voluntary program with a set of voluntary initiatives has the advantage of ease of interpretation for individuals and companies alike. It can be suited to distinctive individual company situations; it can have flexibility with broad and firm principles at the same time. Ultimately, satisfaction should come from the individual, since only he or she can assess the effectiveness of the confidentiality principles that apply, not agencies or representatives of government or consumer groups. Thus, the importance of individual life insurance companies' privacy initiatives should not be understated nor should these initiatives be discouraged. After all, when it comes to medical record information, only specialized disciplines within the business will have responsibility for confidentiality, as they do now.\(^{29}\)


\(^{23}\) Id.

\(^{24}\) Id. at 12-14.

\(^{25}\) Id. at 14-15. See also Latrenta, supra note 3, at 185-188.

\(^{26}\) Supra. note 22, at 4-5.

\(^{27}\) See Latrenta, supra. note 3, at 221.

\(^{28}\) Supra. note 22 at 4-5.

\(^{29}\) Id.
It is submitted that, in this regard, these individuals are best positioned to implement confidentiality principles as challenges present themselves in the medical record area.  

IV. Confidentiality Concerns of the 1980's

When it became clear that the rapidly-developing acquired immune deficiency syndrome ("AIDS") outbreak of the early 1980's had significance for life insurance, the initial concern of insurers was to pursue their ability to make appropriate underwriting decisions regarding the presence of the AIDS virus. Several states enacted AIDS-related laws, with some states prohibiting insurers from utilizing tests for the detection of HIV in the early days.

The life insurance business made it clear early on that traditional confidentiality policies would apply to AIDS-related information. The NAIC Model Act, being a fair information practices law, was not promoted by the business as the only solution to AIDS-related confidentiality issues. In 1986, the NAIC adopted the report of its AIDS Advisory Committee, including a proposal for "medical life-style questions" to prohibit inquiries about sexual orientation, and to prohibit the collection of such information by insurance support organizations.  

As the AIDS issue moved along, there was more and more attention paid at the state level to the confidentiality issue and the issue of informed consent. A number of states enacted laws in the late 1980's addressing both the informed consent and the counseling and confidentiality issue. Several states enacted confidentiality laws that simply proclaimed "confidentiality" as a standard, without elaboration.  

On top of all of this, federal legislation was proposed in mid-1987 to deal specifically with AIDS and confidentiality. This legislation had been under development by Congressman Henry Waxman (D-Calif.), who had expressed serious concerns about the potential for misuse of AIDS-related information. Over the course of approximately one year, the life insurance trade association (HIAA), was successful in working with the sponsor of this legislation in securing important amendments to the bill and clarifying interpretive language in the proposed committee report. The legislation, for reasons unrelated to the substance of the confidentiality portion of the bill, was blocked at the last moment before Congress adjourned due to the threat of a filibuster by Senator Jesse Helms (R-N.C.). However, the experience gained by the life insurance business in narrowing down the scope of necessary redisclosure restrictions was quite useful: It demonstrated to the Congress and the industry alike that the prime reasons for third-party disclosures of sensitive medical and other information were to consummate a business transaction on behalf of an individual who sought the insurance protection in the first place, and not for some frivolous or malevolent purpose. It also demonstrated that necessary redisclosures of medical and other information could be treated in such a way that the business function would be served while, at the same time, protecting the confidentiality of the individual at the highest level possible. In addition, it focused attention on the necessity of permitting limited redisclosures without the individual's authorization, such as in the case of responding to legal process, fraud, etc.  

V. Future Confidentiality Concerns

From the late 1980's, and continuing to the present and beyond, it is clear that one of the most challenging issues of the times will be the handling of sensitive medical information such as that derived from genetic testing if and when it becomes a reality in the medical community. It is expected that with the completion of the Genome Project, technology will be emerging so as to enable at least some genetic testing to be proposed in the medical community. The life and health insurance businesses have stated emphatically that they have no plans in the immediate future for genetic testing in the underwriting process. However, they will, naturally, need access to tests that have been ordered by the individual or his or her physician so as to protect insurers from adverse selection by applicants.  

There are many reasons associated with the unwillingness on the part of personal insurers to engage in genetic
testing at this time or, indeed, in the immediate future.\(^{36}\) One of the main reasons is cost; similarly, an important reason has to do with the lack of predictability and reliability of many such genetic tests vis-a-vis FDA or other official approval. Nonetheless, it is clear that the public and policy-makers will have perceptions about genetic testing on the part of life and health insurers, and will insist on confidentiality of this information if and when it gets into the hands of insurance companies.

In anticipation of these kinds of expectations, the ACLI and the HIAA several years ago appointed a CEO-level task force to examine all of the myriad ramifications of potential genetic testing in the life and health insurance business.\(^{37}\)

An extensive report was prepared, together with a special study of the confidentiality issue prepared by the Privacy Subcommittee of the ACLI.\(^{38}\) These documents speak for themselves, and it is not the purpose here to repeat their findings and conclusions. However, it should be pointed out that in the confidentiality area, the Subcommittee concluded that even though genetic testing is yet an unrefined technology, the life and health insurance business should think ahead in terms of the confidentiality expectations of its insurance-buying public and of the increased concerns that have been raised by government, the media, consumer groups and others. After analyzing the various options, such as federal or state legislation vs. voluntary programs, it strongly endorsed the notion of a voluntary initiative to address this important problem. It believed that simplicity and understandability were most important, and that flexibility was an essential ingredient of any such initiative. Essentially, then, it endorsed four rather simple principles which it believed would serve the business well in the future if implemented on a voluntary, but fairly comprehensive, basis. These principles are:

"Principle One"

A commitment should be made to applicants and insureds alike that, with the exception of several defined specific circumstances, the redisclosure of genetic test information will be made to third parties only with the written consent or authorization of the individual or his/her representative. This consent or authorization could be obtained at the time an application is taken, and would remain valid throughout the lifetime of the policy. It should be specific where possible, e.g., the M.I.B., and generic where otherwise necessary, e.g., re-

insurers, co-insurers, contractors, etc. To the extent practicable, a brief description of the redisclosure purpose should also be made.

Redisclosures without written consent or authorization should, for this type of sensitive information, be limited to the following circumstances:

1. in limited non-discretionary circumstances pursuant to state or federal law, e.g., where required by state insurance regulators, law enforcement authorities, pursuant to subpoena, etc.;
2. where an adversarial relationship exists (or could exist) between the individual and the insurer such as in the area of disputed claims and where fraud detection and deterrence are necessary;
3. in extraordinary situations that usually would not have been anticipated by the individual or the insurer, such as in the case of a sale or merger of the company; and
4. for research or statistical purposes, such as for actuarial-medical studies.

As part of this commitment, and except in the types of situations outlined in (2), insurers should, where the disclosure was recorded, inform the individual of this fact, upon his or her request.

"Principle Two"

All permissible redisclosures should contain only such information as is reasonably necessary for the recipient to perform its function, and the recipient, in turn, should generally be prohibited from making further redisclosures without the specific consent of the individual.

"Principle Three"

Internal operating policies and procedures should be adopted to restrict authorized access to all genetic testing information to only those who are aware of internal confidentiality policies and who also have a legitimate reason to access policyholder information.

"Principle Four"

Insurers should publicize their confidentiality policies and the restrictions they impose on the redisclosure of

\(^{36}\) supra. note 22, at 4-5.


\(^{38}\) Supra. note 22, at 4-5.
In discussing these four principles, the Subcommittee stated the following:

The centerpiece of virtually all confidentiality programs is the individual's ability to exercise some amount of control over the further disclosure of information originally furnished to an organization as part of a business or other similar transaction. Thus when it comes to sensitive medical information provided in confidence to another party, a basic expectation of confidentiality is that there will be no further disclosure to third parties without some form of express or implied consent or authorization. The more rigid versions of this confidentiality principle insist on specific, item-by-item "permission." More pragmatic variations, such as those recommended by the Privacy Protection Study Commission in 1977, call for advance consent or authorization of the individual and generic as well as specific descriptions of the recipients. Many confidentiality programs also include a description of the redisclosure purpose, where the generic reference is not descriptive, e.g., contractors for claims purposes.

Principle One contains this basic pledge, and envisions both specific and generic consent or authorization language, much like that in current usage by many insurers. The consent or authorization could be obtained at the time of application, and would remain valid throughout the lifetime of the policy. Four "exceptions" would come into play without consent or authorization, and are the basic ones that have the most significance as a matter of operating experience in the life and health insurance business. Taken as a whole, Principle One recognizes that (a) consent or authorization is required for almost all genetic test information, and (b) limited redisclosures that will not compromise the individual's expectation of confidentiality are necessary in some circumstances without the individual's consent or authorization.

Principle Two simply reinforces the confidentiality assurances stated in the first principle, so that when redisclosures are in fact made, they will contain only information reasonably necessary for the recipient to perform its function. For example, if a redisclosure is made to a contractor for claims purposes, Principle Two would envision furnishing only such information to that contractor as was reasonably necessary for the performance of the particular contractor's function. In addition, Principle Two states that when a redisclosure is made, the recipient will, in general, be prohibited from further redisclosure without obtaining the specific consent of the individual involved. This is an important feature of most confidentiality initiatives.

Principle Three recognizes the need for internal operating policies and procedures to restrict authorized access to persons who have been instructed in the confidentiality policies of a particular company, and who also have a legitimate business reason to access policyholder information.

Principle Four simply calls for companies to publicize their confidentiality policies and restriction on redisclosures to those who have potential needs for sensitive information. Implementation of this Principle would also give publicity to the confidentiality initiative.

There will be a great deal of debate when genetic testing becomes a reality as to whether it should command a standard that is "higher" than other sensitive medical information. There are arguments on both sides of this issue, and no attempt will be made here to resolve this dilemma. Suffice it to say that where programs and initiatives have addressed confidentiality in the past, it will undoubtedly be convenient to expand such programs to embrace new emerging medical technology such as genetic testing and other future medical tests or markers that may have the same sensitivity. The flexibility requirement mentioned previously will be quite important since individuals must be making decisions on a day-to-day basis about what standards should apply to such information. This cannot be anticipated by legislation or regulation, and what is more, enforcement mechanisms do not always produce the most desirable results when it comes to what sometimes are quite subjective and individual decisions based on professional experience and knowledge.

39 Supra. note 22, at 4-5.

40 Id.
VI. Commentary on Life Insurers' Policies and Procedures for Collecting, Using and Disseminating Medical Record Information

A. Methods of Collection

Because the chief functions of a life insurer involve underwriting individual risks, the decision-making process that is brought into play must involve the evaluation of applicants and their individual risk characteristics. For this reason the life insurance business is probably one of the largest private sector gatherer and user of information about individuals. When it comes to medical information, because of the significance of this information for life insurance, it is fair to say that many thousands of transactions occur each day within the life insurance business where medical information is sought as a part of the application process.

What may not be apparent is that, while this information is central to evaluating the life insurance risk, the use of medical information obtained from third parties does not occur in all cases. Most medical information comes from the applicant, and is a part of the application process, where a number of questions are answered by the applicant concerning family medical history, and medical treatment and diagnosis. When third-party information is sought from health care providers, such as attending physicians or hospitals, this is only done with the authorization of the individual. Thus, it should be understood very clearly that "unauthorized" access to medical information is not a problem in the life insurance business.

Because of the focus of public policy groups and government on the role of the computer in storing medical information, it is appropriate to make the point here that, with few exceptions, life insurance companies do not utilize the computer to access medical information during the underwriting and claim process. The information, as authorized, will arrive in the company in "hard copy" form, and will be used in this format while the application or claim is being considered. In a number of companies, the paper file will be converted to microfilm or microfiche, and the paper file will be destroyed after a period of retention. To the extent the computer will come into play, it is increasingly likely that it will be in the use of "imaging technology," whereby the paper is "imaged" onto a laser disk in lieu of being microfilmed. The vast majority of life insurance companies have not seen fit to adopt imaging, and it must be understood that this is merely a substitute for microfilm. Importantly, it must be recognized that life insurance companies have not, at present, been able to discern benefits from computer storage of medical information data that they have seen in other areas, for instance, in premium billing. Nor does it seem probable, outside of imaging, that this will be a likely development. With the exception for this reason, there should be little public policy concern about computer security issues, at least for the life insurance business.

B. Correction Procedures

Some mention should be made of correction procedures with respect to medical record information. Even before the advent of formal and informal fair information practices policies, most life insurance companies had some means in place for correcting medical information that may have, for whatever reason, proved to be inaccurate or incorrect. The motivation behind this, obviously, frequently eludes privacy advocates, but is quite basic. Every insurance company has the incentive to treat its customers as fairly as possible, just as it has every business incentive to place the policy, and not act adversely with respect to it.

When the NAIC Model Act was adopted, and when companies voluntarily adopted privacy policies, the correction procedures for personal information became, essentially, the correction procedures for medical information. There is a right to access and correction, not only as part of the adverse underwriting decision process, but at any other point in time with respect to personal information that an insurer may be holding.

An example might be helpful to this discussion. Assume that in the course of underwriting an application, a life insurer received recent medical information from an attending physician, including a chest X-ray with a doctor's diagnosis, and a concurring radiologist's opinion, indicating that the proposed insured had an enlarged heart. The insurer agrees to issue a policy, but because of the heart condition, in a substandard classification, for an additional premium. The company also makes a report in coded form to the MIB about this condition. The insured, upon learning of the adverse underwriting decision (the substandard classification), writes to the company and, pursuant to the procedures of the NAIC Model Act, asks that the insurer disclose

41 The retention period is usually related to state insurance regulatory examinations of insurance companies.

42 NAIC Insurance Information and Privacy Protection Model Act, Section 9.

43 As indicated earlier, many insurers adhere to the "adverse underwriting" and other provisions of the Model Act as a voluntary initiative, even though the transaction is not legally subject to the Act's proscriptions in the particular jurisdiction.
the specific reasons for its underwriting decision to his or her attending physician. This physician happens to be the same doctor who provided the original medical information upon which the decision was based.\textsuperscript{44} The insurer’s medical director writes to advise the physician that the decision was based on a diagnosis and a copy of an X-ray that the doctor provided. The doctor responds, and supplies supporting documentation that a cardiologist evaluated the proposed insured and determined that the original X-ray film was not clear, and ordered two new X-rays, two weeks after the date of the application. On this basis, the cardiologist and the insured’s primary physician revised the diagnosis, and determined that the X-ray was inaccurate and that the insured did not in fact have an enlarged heart. On learning this, the insurer agrees to improve the rating from substandard to standard. Also, because a coded impairment report of the earlier X-ray was made to the MIB, the insurer notifies the MIB to correct the code, pursuant to the NAIC Insurance Model Act, as well as MIB’s own rules.

C. Confidentiality Policies and Security Concerns

The point has already been made that, even absent formal and informal privacy confidentiality policies, the life insurance business has long held the belief that confidentiality about its customers is a fundamental and paramount value. This is not only true from a company policy standpoint, but translates to day-to-day operations in sensitive areas of company operations, such as underwriting and claims. The general rule is that only those with a business need to know may have access to any information in the hands of underwriters, and the same is true for claims operations. This has been the standard operating procedure in the industry for many years, and the vast majority of companies have formal means of expressing their confidentiality commitments to their employees, with serious disciplinary consequences for those violating such commitments.

D. Influence of Ethics, Medical Professionals and Public Policy

In recent years, with the advent of more sophisticated medical underwriting, the medical director’s relationship with the underwriting departments of companies has become much stronger, due to the increased significance medical testing has attained. For this reason, there has, indeed, been a re-emergence of the medical professional ethic with respect to how tests and other sensitive information are handled within the companies, and when redisclosures are required, to third parties. This, again, is an example of individual company initiative, with the same goal of protecting sensitive information from unauthorized disclosure and redisclosure. All of this is brought back to the fundamental premise that it is in the interest of all insurers to take precautions on behalf of their customers because of the confidential nature of the transaction in the first place between the individual and the insurance company.

VII. Conclusion

Clearly, in any business as large and as important as the life insurance business, there will always be room for improvement, whether it be by way of better policyholder information and service, or redoubling the commitment to fair information practices and confidentiality standards. Nonetheless, the life insurance business has a proud tradition over many years of maintaining confidentiality on behalf of its customers. This commitment has been buttressed along the way during the public policy debates of the 60’s and 70’s, the AIDS crisis of the 80’s, and the expectations of the 90’s.

In the 90’s and beyond, the clear challenge will be a demonstration of renewed commitment to confidentiality, as the business deals with genetic testing and other sensitive medical information that may find its way into the hands of insurers. The challenge is there, and, based on the markers over the last century, the industry will certainly measure up to its commitment. The specific voluntary confidentiality principles recommended by the industry’s experts will be implemented on an increasingly larger scale as it moves closer to the genetic testing debate. Not every company will adopt the same apparatus, but what is significant and should be impressive, is that the industry’s concern for this issue has driven its commitment, even before the public policy debate began. And this concern, it is submitted, will serve the life insurance business and the public well in the future, as continuing confidentiality challenges are presented. After all, the life insurance business depends, in the long run, on its commitment to individual prerogatives and the confidence of these same individuals in the integrity of the business, including, among other things, how it meets the confidentiality challenges of the future.

\textsuperscript{44} While the Model Act calls for disclosure of medical information to the "physician of choice" in most jurisdictions where it has been adopted, there is clearly a trend toward direct disclosure to the individual, and in fact, this disclosure method was endorsed by the American Council of Life Insurance Medical section Board of Managers in 1991.