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An
**UNFORTUNATE
EXPERIMENT**

at
***National
Women's***

by SANDRA CONEY
and
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IN OCTOBER 1985, RUTH (NOT HER REAL NAME, FOR LEGAL REASONS which will become clear later in this story) returned from National Women's Hospital and told her workmates she felt she'd just been to Auschwitz. "I feel as if they've been experimenting on me," she said. Ruth's fellow teachers thought she was being ridiculous and said so and so she pushed her doubts to the back of her mind.

It was over 20 years since Ruth had made her first visit to National Women's Hospital. She had not been a teacher then, but a 27-year-old suburban mother of three small children. She had failed UE and with "the disadvantage of no education" remembers herself as "the sort of patient who meekly did what she was told."

She had been referred to the hospital by her general practitioner after a "suspicious" cervical smear. Having a cervical smear means that cells are collected from the surface of the neck of the womb using a sort of ice block stick, then smeared in a thin film across a glass plate so that their structure can be seen through a microscope.

At the hospital Ruth was told that though her smear was "suspicious", nothing more serious was going on. She came home and reassured her husband that she didn't have cancer and that there was nothing to worry about. "That", she remembers, "was the frame of mind they put me in from the beginning."

Six months later she had an examination of her cervix with the colposcope, a powerful magnifying instrument, and a single punch biopsy removed a fragment of tissue the size of a rice grain for scrutiny in the pathology laboratory. In the space of the next six months, Ruth had three colposcopies and three smears were taken. She felt confident that she was being carefully watched.

In mid-1965, Ruth became pregnant. Her GP was surprised when she told him about the pregnancy. "What do they think at National Women's? he asked. Ruth told him the doctor she saw at the hospital said it was fine and her GP agreed that he must know what he was doing. In March 1966, Ruth gave birth to her fourth child, a healthy eight-pound girl.

Sandra Coney is an Auckland freelance journalist. She is a former editor of *Broadsheet*. Her last story for *Metro* was about Pita. Phillida Bunkle is a Wellington academic. Both are connected with *Fertility Action*, a pressure group concerned with women's health choices.

PHOTOGRAPH BY JOHN REYNOLDS

THE DOCTOR Ruth saw at National Women's Hospital was Associate Professor Herbert Green. What Ruth didn't know was that Green was carrying out research on his patients and that her case had already been written up in a medical magazine.

Herb Green was an expert on cervical cancer. He was on the world circuit, attending conferences and publishing frequently on the subject in prestigious gynaecological journals. From 1956 to 1982 when he retired, he saw virtually every woman at National Women's Hospital with invasive cervical cancer and many of the women who had earlier or "precursor" stages, a total of some 1800 women.

Green was born in Balclutha in 1916. He qualified from Otago Medical School in 1945, where he had won his rugby blue. A Southland representative cricket player, he was a powerfully built man who towered over his colleagues. In 1948 he took a position as house surgeon at National Women's Hospital in Auckland. He immediately became involved in the treatment of cervical cancer.

National Women's was in its infancy. It had opened in 1946 to provide for the post-war baby boom.

The powerful Obstetrical and Gynaecological Society, wishing to consolidate its power by controlling the teaching of obstetrics and gynaecology, pushed for the establishment of a post-graduate school based at National Women's. With the support of the Auckland business community, it endowed a professorial chair. An Australian, Harvey Carey, took over the position in 1954. Carey was liberal in his views, and would ultimately fall foul of the obstetricians by advocating less medical interference in childbirth and opposing a specialist monopoly of the planned unit. Carey was also keen to test the use of cytology in the detection of cervical cancer.

National Women's Hospital had inherited responsibility for the treatment of cervical cancer from Ward 4 at Auckland Hospital. It took cases from the whole of the northern half of the North Island and by 1954 a specialised clinical team had been set up.

Invasive cervical cancer is described as "the most miserable of cancers". In the days before cytology it was not always detectable until at an advanced stage when there would be the unusual bleeding from the uterus or a visible growth on the cervix. The only treatment was by deep ray or radium, although in the early 50s surgery was introduced at National Women's as an additional treatment. In-

vasive cancer was thought to go through earlier or "precursor stages". These stages were called dysplasia, or abnormal cells, the most abnormal cell being called carcinoma in situ or CIS (pronounced kiss). CIS was believed to finally progress to invasive cancer.

A smear from the cervix might reveal cell changes in the earlier stages. The theory was that if cancer could be detected before it reached the advanced invasive stage, it might be possible to remove it and cure the disease.

Carey knew that at nearby Greenlane Hospital Dr Stephen Williams' cytological smear tests of sputum had been successful in detecting unsuspected lung

Professor Green became a man with a mission. He wanted to save women from mutilating surgery and to do so he had to prove what at first he had suspected and eventually came to believe: that CIS was a harmless disease which hardly, if ever, progressed to invasive cancer.

cancer. He knew too that in New York, Dr Papanicolaou, inventor of the "Pap Smear", was "booming away about his cause". Carey went to Williams, and as Williams recalls, begged him to do a trial run of 1000 cervical smears of women entering the hospital for other causes. "Of course", he remembers, "long before we had done 1000, at about the two hundredth specimen, we had turned up an extraordinary smear of carcinoma in situ with cancer cells spread right across the smear. There had been not the slightest sign of cancer on her cervix. Carey was dumbfounded. We did a biopsy tissue test of the cervix and discovered loads of CIS in the tissue."

With this success, the programme did not stop at 1000 smears. It continued and a full-time cytologist was appointed to National Women's to set up a laboratory and train staff. He was sent to the United States to study cytology at first hand, and on his return the Papanicolaou grading sequence was introduced. By 1957 the "Pap Smear" was offered to all doctors in New Zealand.

Carey was evangelistic in his belief in the benefits of screening. Remembers Williams: "Carey raced around like a bee in a fit. He wrote an article for the *Woman's Weekly* saying that cervical screening could save lives. He concluded that he could save five lives for every 1000 smears, a wildly exaggerated claim

as it turned out."

By 1964 the hospital cytology service was seeing 20,000 specimens a year. The year before, National Women's had shifted from its original Cornwall Hospital premises to new \$3 million purpose-built premises in Claude Road, Epsom.

It also had a new head, Londoner Dennis Bonham, elevated to the status of professor from a position as lecturer at University College Hospital, London.

A new cytology block was put out to tender in 1964, but by this time Herb Green had stepped in and said he was having doubts.

Green had joined the cervical cancer clinical team in 1955. He and another colleague had done a limited number of smears in 1948, but he had been out of the country when the major initiatives on cervical cancer were taken.

Green wasn't convinced of the idea of progression of the disease, that carcinoma in situ developed into the potentially fatal invasive cancer. He argued that invasive cancer was probably a quite separate disease. His theory was that if there was little or no progression, then CIS was not a harmful disease and screening for cervical abnormalities would not lead to a reduction in the incidence of invasive cancer. This was the position he would express for the next two decades.

When Ruth first visited National Women's in August 1964, she had no idea that there was any debate about cervical cancer or that her doctor held controversial views. She was quite sure she was in the best of hands. She was put on the waiting list for a cone biopsy, an operation which removed a cone-shaped core at the cervix which could be checked to see that all abnormal tissue had been taken.

But the day following her admission for the cone biopsy, after preparations for the operation had been made, Professor Green told her that he had decided against operating and she was discharged without any treatment.

Every few months after this Ruth was recalled to the hospital where she had further smears, colposcopic examinations and occasional punch biopsies.

The purpose of a punch biopsy is to diagnose what the disease is and how far it has gone. It enables the pathologist in the lab to scrutinise a small section of the cervix under a microscope, look at the cells and say what they are doing. Very occasionally a punch biopsy can cure CIS, but it is most unlikely as the sample is so minute. It has never been regarded as treatment for cancer.

Treatment involves more extensive surgery to remove the cancerous cells, the object of any treatment being to return to a negative (normal) smear later.

Ruth's first punch biopsy in 1965 showed carcinoma in situ, a diagnosis which would be consistently entered on her records for 15 years. Her smears were almost invariably positive (abnormal), and the reports described the cells as "suggestive" or "strongly suggestive" of malignancy. But this Ruth did not know.

Many years later, in 1985, Ruth would see her hospital file and finally know that from her first visits she already had carcinoma in situ. In 1964, and over the years, the words were never mentioned.

By May 1967 the colposcopist entered in her notes that he had observed that the abnormal area on Ruth's cervix had increased in size in the two years since the first colposcopic examination. By the end of that year he recorded "progression both in extent and degree". Throughout 1968 and 1969 Ruth's smear reports were "conclusive for malignancy". But still nothing was done.

In March 1970 Ruth was admitted for a curette of the uterus (a scraping out of the lining of the uterus) and wedge biopsies.

A wedge biopsy takes a rather larger piece of tissue than a punch biopsy but it is also used mainly for diagnosis although rarely it can be a cure. Ruth's pathology report showed carcinoma in situ in all the specimens and in one "micro-invasion of the cervix". This is the first sign that the cancer is penetrating deeper layers of cells and becoming invasive.

Despite this, Ruth was again discharged. She returned for smears right through 1970, each one showing cells still "strongly suggestive" or "conclusive for malignancy". Ruth still had the disease and still did not know it.

RUTH WAS NOT the only patient Professor Green was studying. Between 1962 and 1974 he wrote numerous papers for the medical journals detailing his experiences with women with CIS and cervical cancer at National Women's.

It was experience with young childless women which started Herb Green asking questions about the diagnosis and treatment of cervical cancer.

By the early sixties, the idea of the progression of cervical cancer through precursor stages was generally accepted in the medical community. But the disease was not completely understood and there was room for argument. The causes of cervical cancer were not known. How often it progressed and how quickly, was the subject of debate. It was strongly argued that widespread screening programmes would reduce the incidence of cancer by detecting it earlier and the large programme underway in British Columbia, Canada, was being watched with interest.

Women with abnormal smears were customarily investigated further by biopsy to diagnose more accurately the stage of the disease. The standard treatment for the precursor stages was cone biopsy.

Cone biopsy is described as a "nasty operation". Haemorrhage needing emergency treatment is not an uncommon problem and the woman's chances of conceiving afterwards can be significantly reduced. The cervix can be so scarred that menstruation can become difficult and very painful.

For carcinoma in situ the standard treatment was hysterectomy, a major operation involving removal of the uterus or womb which therefore rendered the woman sterile.

Twenty-five years later Herb Green can remember in vivid detail some of the cases which distressed him most. A young poet had her university degree conferred in a ceremony in Ward 9 a week before she died of cancer of the cervix. "When you see a young attractive woman who'd make a wonderful friend for a man a little younger than myself, when you see her die, it's not nice. That's why I've been so vocal. This is bad for mankind. I realised at the time she wasn't the only one under 30, there were four," he recalls.

He remembers too another patient who gave him the clue which formed the basis of his theory. He calls her "the little girl who put me on the right track". Green performed a biopsy disclosing CIS, but the woman "refused a hysterectomy". "Two years later she had a baby. She's still alive, living somewhere round Whenuapai."

Green was concerned at any reduction in women's fertility. He was an opponent of abortion and with his gynaecologist colleagues Patrick Dunn and William Liley, later played a leading role in the early days of the Society for the Protection of the Unborn Child (SPUC). He took such an uncompromising view of abortion, calling it murder, that he was used to present the extreme anti-abortion view to Auckland Medical School students. At one stage he caused a furore at National Women's by refusing to work with doctors performing abortions.

On sterilisation he also held conservative views. He could see virtually no grounds for it, medical or social, arguing that abstinence would lead to the desired result. Once sterilised, he said, a woman had "thrown away a unique possession".

Professor Green became a man with a mission. He wanted to save women from mutilating surgery, and to do so he had to prove what at first he had suspected and eventually came to believe: that CIS

was a harmless disease which hardly, if ever, progressed to invasive cancer.

Green's belief led him to treat some patients less extensively. He stopped performing routine hysterectomies in women with CIS and instead performed cone biopsies, checking by pathology (tissue diagnosis) that the complete tumour had been removed. By 1962 he was able to report that no patients treated this way had progressed to invasion.

Time had shown that Green was correct in arguing for more limited treatment of CIS patients. Many women were saved from unnecessary hysterectomies, and by the mid-sixties cone biopsy for CIS had become standard treatment.

Having made a breakthrough and having produced what looked like support for his hypothesis, Green pushed the limits of his theory further. Many other medical authors had published papers in the fifties and early sixties estimating that CIS progressed to invasion in a variable proportion of cases. Green proposed "to show that the lesion is probably benign in the great majority of cases" and to question the view that screening programmes could eliminate invasive cancer.

He began to treat small groups in unorthodox ways. At least five women, and possibly as many as 16, had hysterectomies without prior biopsies to diagnose what was happening to the cervix. Green had only looked at the cervix with the naked eye and taken a Pap smear. A Pap smear can reveal an abnormality, but a biopsy is necessary to accurately say what stage the disease is at. Earlier, Green had always argued that biopsies were vital for proper diagnosis. In these cases he'd omitted this step. One result was to provide him with intact cancer lesions to study in the laboratory.

In Green's words, these patients formed a "special series wherein invasive cancer has been ruled out as far as possible by clinical [looking and listening to the patients] and cytological methods before hysterectomy; serial section studies of lesions thus undisturbed by biopsy are being made and will be reported separately."

There were two dangers in performing a hysterectomy without biopsy. First, a healthy uterus might be mistakenly removed. Second, and possibly fatally, if the woman, in fact, has invasive cancer, it would be difficult to treat optimally with radiation therapy after a hysterectomy. In this treatment, radioactive rods are inserted through the cervix to sterilise the uterus and adjacent tissue. With the womb removed, the rods could not be put in place.

Because in these cases Green had not done biopsies before surgery, the only way to detect the seriousness of the disease and see if more treatment was needed, was to immediately examine the excised wombs in the pathology laboratory. Before this could be done, Green took some of the wombs with him to New York when he left in 1962 on a year's Lederle Scholarship.

Two months later, National Women's received a note from New York. Green was reporting that one of the wombs had shown the woman actually had invasive cancer at the time of her hysterectomy. Despite more extensive surgery, she died two years later.

In other groups of patients the abnormal tissue was not completely removed, or Green "temporised" — that is delayed — further treatment, despite positive smears continuing after cone biopsies. This, he acknowledged in writing, "may appear foolhardy to those who believe in a high chance of progression of the disease to invasion".

Although it is clear from Green's writing that he knew his was a minority view, and that he was providing unorthodox treatment, he did not think the patient should be the one deciding: "If we are uncertain about the natural history of the disease which cytology has revealed in her, how can we possibly expect her to make what is really our decision?" he asked.

Green justified his unusual handling of cases by insisting that he always rigorously excluded the possibility of invasive cancer before deciding on limited treatment. He also produced his results in vindication of his methods. For much of the sixties he insisted that not a single case had progressed to invasion.

In April 1963, Green embarked on another study. Between this date and June 1965 the rate of cone biopsy at National Women's doubled, peaking at 140 operations annually before falling to below 40 in 1966. Wrote Green: "200 [cone biopsies] were performed by the author as a special study", one of the aims being to "estimate in a consecutive series" the correlation between the grade of the prior smear with the later histology (tissue diagnosis) report. In nine women, the smears had showed nothing wrong. Their cervixes were only coned because they "looked suspicious".

In fact, the post-operative histology reports showed that five of these women had only cervicitis, a mild inflammation of the cervix in no way requiring such drastic treatment.

By the mid-sixties Green was so convinced CIS was harmless, he even argued against the necessity for cone biopsy, a

proposition he decided to test by omitting the cone biopsy on some women. This could have been the reason for the cancellation of Ruth's cone biopsy in 1964.

In June 1966 Green formalised his experiment and gained permission from the Hospital Medical Committee to manage a group of women "conservatively", that is, to withhold conventional treatment of cone biopsy or hysterectomy. The women selected were under 35 and the possibility of existing invasive cancer was excluded by punch biopsy performed by a colposcopist looking at the magnified cervix.

Colposcopy was introduced to National Women's in the mid-sixties. The colposcope sharpened the view of the cervix, enabling abnormal cells to be seen in a way they could not be by the naked eye. The site for biopsies could then be carefully chosen, rather than the more random method of the past.

In the women Green managed "conservatively", the lesion was to be damaged as little as possible by the biopsy, and despite continuing abnormal

Some women with evidence of disease were to be left. They would be followed — that is, brought back for regular smears and possibly more biopsies — but there was no intention to cure them.

positive smears, the women were to get no further treatment.

Other women who had abnormal smears after initial treatment, such as cone biopsy or hysterectomy, were also to receive no more treatment. According to a paper by Green, by the end of 1966, some 73 women with evidence of persistent, uncured CIS were being followed. Twelve of these had diagnosed microinvasion of the cervix. Sixteen had only had a punch biopsy.

Differences of opinion over the best treatment for CIS were one thing but there was always unanimity in the medical community about the object of treatment — to return to a negative or normal smear. A positive smear was a sign that treatment had not been successful, that there was still disease present and there had been no "cure". In such cases, further treatment was called for, until the smear became normal.

This was never the intention of the National Women's experiment. Some women with evidence of disease were to be left. They would be followed — that

is, brought back for regular smears and possibly more biopsies — but there was no intention to cure them.

The dangers of this are many. If the initial diagnosis was inaccurate, women might be unwittingly harbouring an advanced stage of the disease. Women might ultimately need unnecessarily extensive treatment to cure invasive disease. They might even die, for once the cancer has become invasive, treatment will not always halt the disease. In addition, if they failed to attend for follow-up, missed appointments or moved overseas, they were at serious risk.

But by watching these women, Green hoped to observe the natural history of the disease and prove his thesis, that untreated CIS rarely, if at all, led to invasion.

The words "natural history of the disease" are important and need to be emphasised. "Natural history" means what the disease will do if it is not interfered with by medical treatment. Many overseas researchers interested in cervical cancer would very much have liked to study the natural history of cervical cancer, but it was considered unethical to do so. If you believed in the progression of the disease, as they did, you could not risk women's developing the potentially fatal form by not treating its precursors.

Asked to comment on this study, Leopold Koss, Professor of Pathology at Montefiore Medical Centre and Albert Einstein College of Medicine in the Bronx, New York, the leading world authority of cytology, wrote: "...there is excellent evidence that not all of these precancerous lesions progress to cancer, hence a large number of them might be presumed to be unnecessarily treated. Dr Green stresses this point repeatedly in his papers, and as far as this issue is concerned he is completely correct.

"On the other hand, neither he nor anyone else can predict which one of the precancerous lesions will progress to cancer and which will not. Therefore all must be treated.

"Dr Green is a senior and generally respected gynaecologist who is a well-known contrarian. I must stress though that most serious observers of the cervix cancer scene do not agree with his views."

Dr David Boyes, director of the Cancer Control Agency of British Columbia and author of the studies which have convinced the rest of the world of the efficacy of cancer screening makes a similar comment: "...unless the whole lesion was removed, it was not possible to know whether there was some begin-

ning invasion. We have never considered that it was appropriate in man to study the natural history in this fashion because one never knew what one was dealing with unless the whole lesion was removed."

Ralph Rickart, Professor in Pathology and chief of the division of Obstetrics and Gynaecology, Pathology and Cytology at Columbia University College in New York, is more forceful. He doesn't think the study should ever have been started. "By the late fifties, and certainly by the mid-sixties, there was little debate on the fact that CIS progressed. The weight of evidence at the time was that CIS progressed. The weight of evidence at the time was that CIS was a precursor. Others had conducted long-term studies on the disease, but had used CIS as an end point. It was absolutely unacceptable and unethical to follow people past that point."

Rickart believes that most cancer lesions progress if the women live long enough for that to become evident. "At best," he says, "75% will progress within 10 years."

There was debate about progression in the sixties, but the debate in the rest of the world was about the progression rate, not whether it did or did not progress.

In one of his papers, Green quotes the famous New Zealand gynaecological specialist, Professor Stallworthy, Professor of Obstetrics and Gynaecology at Oxford University, as having said in 1966: "To regard carcinoma in situ as not being a killing disease is comparable to giving a stiletto to a paranoiac."

In another paper Green quotes the opinions about progression held by others at this time: Dunn et al (1959) 100% progression rate, Lange (1960) 33.3% progression rate, Boyes et al (1962) 60%, Graham et al (1962) 10-20%, McGregor and Baird (1963) 33.3%, McGregor (1966), 100%.

These figures are quoted to show that Green was out on a limb. His opinion was not shared by the medical community and he knew it. A 1970 paper in an Australasian medical journal was headed *An Atypical View*. In it Green said that by "commonly accepted standards, many in-situ lesions have been almost disdainfully under-treated", and that "It is clear that the author's experience with cervical carcinoma in situ is at considerable variance with that of the great majority of others." He called others' belief in progression a "dogma" which had become "immutable and almost unchallengeable" and so he set about challenging it.

Professor Green described the purpose of the experiment this way: "The only way to settle finally the problems of what happens to in situ cancer is to follow indefinitely patients with diagnosed but untreated lesions. This is being attempted."

Discussion of the ethics of the study never appeared in his papers, perhaps because he believed so absolutely that women with CIS would not develop invasive cancer. Green has written: "If the physician does not worry too much about the disease then neither will the patient."

Consequently, patients like Ruth did not know they were being studied, nor that they were being treated in an unorthodox way.

In his paper *The Natural History Of Cervical Carcinoma In Situ* Green described the arbitrary manner in which women were selected. "No clear pattern of selection is discernible, and subsequent treatment was most often a matter of chance, dependent on the views of the consultant under whom the patient was admitted — and, therefore, really on what day of the week the patient was referred to the clinic."

It has been impossible to discover whether all the patients given limited treatment were Herb Green's. Neither the

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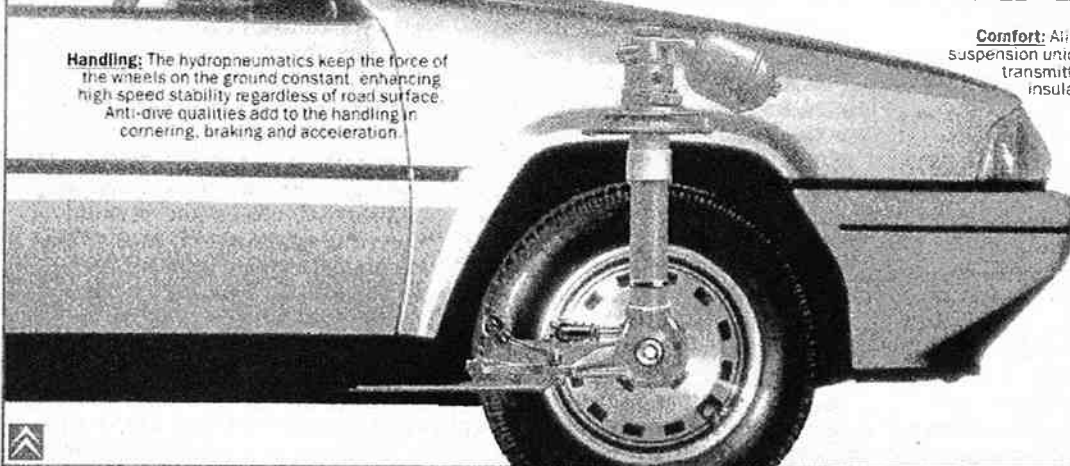
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Professor Dennis Bonham... he OKed Green's study.

present medical superintendent of the hospital, Dr Gabrielle Collison, nor the head of the postgraduate school both then and now, Professor Dennis Bonham, could answer this question, although Bonham said other doctors referred CIS cases to Green "because of his interest".

In answer to a question about whether women were told there were differences of opinion about the methods of treatment, Green replied: "I suppose not."

In answer to the same question, Professor Bonham said: "I wouldn't know, you would have to ask each individual doctor who treated patients."

There was no hospital plan to seek the agreement of the women to their unorthodox management. Thus, like Ruth,

they were unaware they were getting anything other than standard management for their disease.

In 1966 there was no ethics committee in the hospital. At that date, no hospital in New Zealand had one. The study was passed by the Hospital Medical Committee of which Bonham was chairman.

But despite the lack of an ethics committee, international standards for human experimentation did exist.

Ethical standards for human experimentation had been set by the Nuremberg Code in 1947. The code was the first serious attempt to produce a universal code of conduct for doctors and scientists engaged in medical research involving human experimentation. It formed the basis for all subsequent

codes, most notably the World Medical Association's Declaration of Helsinki, first issued in 1964 and revised in 1975. Its central principle is an unequivocal statement of the need for informed consent.

The National Women's experiment, it appears, violated most articles in the code.

In 1971 Ruth attended the National Women's colposcopy clinic where the colposcopist, Dr William McIndoe, observed "dramatic changes" in her cervix. The abnormal area visible under the microscope had increased. McIndoe arranged for Ruth's admission for a cone biopsy which Green performed a month later. The histology report showed microinvasion of the cervix and that the tumour had not been completely removed.

When Ruth returned eight months after the operation for a further colposcopic examination, McIndoe was worried about a small area of unremoved abnormality extending into the vaginal wall and her continuing positive smear. "I would be more satisfied clinically and scientifically," he wrote, "since this should be quite possible quite safely and readily, to remove this small area which remains."

Green was out of the country and McIndoe performed the operation himself. The tissue he removed showed carcinoma in situ.

In 1971, for the first time in seven years, Ruth's next smear was relatively normal with no evidence of malignancy, though this would not last. By the end of the year, she was once again showing evidence of malignancy. Despite this, for some reason, Ruth had no colposcopic examination by Dr McIndoe after 1972.

BY 1971, Dr Bill McIndoe was a worried man. He did not like some of what was happening at National

Women's. For more than 10 years after he arrived at National Women's he was the only colposcopist in New Zealand. He trained many practitioners of the new specialty in his clinic. From the time he arrived he worked closely with Associate Professor Herb Green and was the colposcopist for all the women being studied. He was in the position of observing lesions which in any other hospital would have been removed.

Cytologist Dr Stephen Williams describes McIndoe as "professionally very careful, exact and accurate. He was a worrier to some extent, and at times he was in an enormous dilemma about all this business."

According to a later colleague: "He was worried sick about it. He could see

people dying and that the standard wisdom being taught was wrong."

Bill McIndoe is called by those who knew him "very religious", "a lovely bloke" and "shy". He died in late 1986, of a heart attack, aged 68.

For 20 years Bill McIndoe opposed what he saw happening at the hospital. On June 20, 1966, when Green put forward his proposal to study the natural history of cervical cancer on National Women's patients, McIndoe objected. At the senior staff meeting he outlined his fears in a memorandum to which he spoke at length: "At our present state of knowledge, rather than swing to an extremely conservative position with respect to treatment, I feel the correct measure would be to aim to remove tissue responsible for the positive smear." He called Green's management "inadequate" both from the point of view of diagnosis and treatment.

However, McIndoe was not a member of the Hospital Medical Committee, the elite group which controlled practices at National Women's. The HMC was chaired by Professor Bonham and comprised the superintendent, Dr Algar Warren; Green; leaders of the hospital's clinical teams; the radiologist; and the head pathologist.

Later in the day of June 20, 1966, the HMC approved the Green proposal. McIndoe did not get a chance to express his views at this meeting, views which apparently were supported by at least some of the non-HMC medical staff.

The dangers McIndoe saw were twofold. First, that by limiting diagnostic biopsies, a smouldering invasive cancer could be missed. Second, that by delaying treatment or not completely removing abnormalities, risks were being taken with women's lives.

It was an unequal battle. At this stage McIndoe's was a lone voice. McIndoe is described in his obituary as a "kindly self-effacing man of complete integrity [who] could not abide sham or hypocrisy in any form. He was a good man whose high principles showed up strongly in his whole life..."

Had he not believed so passionately in the wrongness of the National Women's experiment, McIndoe would have been content to work behind the scenes, developing the scientific basis of cytology and colposcopy. He had come late to medicine, after training as an electrician, and when he arrived at National Women's he never quite fitted into the powerful inner group which ran the hospital. It was this unlikely person who challenged Associate Professor Herbert Green.

Almost everybody, supporter or oppo-

nent, comes up with similar descriptions of Herb Green. "Domineering", "belligerent" and a man who could not bear criticisms, are the opinions of his detractors. A member of the non-medical staff who described Green affectionately as a "kind, cuddly teddybear of a man" also talked of his propensity for "getting on his high horse. He was right and everybody else was wrong. He always had the last say."

McIndoe's struggle to end the experiment is called by a friend "the battle of his life". His attempts became more desperate as the tragic scenario he

McIndoe became "worried sick" about what he saw happening. He could see people dying and how the standard wisdom being taught was wrong. For 20 years Bill McIndoe opposed what he saw happening at the hospital.

predicted unfolded in the cancer clinic. It was McIndoe who was operating the colposcope, who could see through its powerful magnifying eye the troubling abnormal patches on the cervixes of the women he examined. When these women were brought back again and again without the treatment he could see they needed, he could not bear it. Green was the consultant and had responsibility and ultimate control over treatment. McIndoe could not interfere directly in the consultant's clinical judgement. "I have been powerless to intervene," he wrote.

Although McIndoe found Green "difficult to cope with", he persistently challenged him in memoranda and in person. In 1969 in a long memo he discussed disagreements about specific cases. Later, in 1972, he and Green locked swords on five occasions, once prompting Professor Mont Liggins to interrupt them by asking "Are you two still at it?" McIndoe described these confrontations as "vigorous interrogations".

The response, said McIndoe at the time, was that Green "not only will not, but does not, listen to any comment which does not suit him. I have endeavoured by all means possible in a mature and dignified manner to make my feelings plain..."

Beginning some time in the late sixties McIndoe began keeping a list of patients "who were causing concern". As the

years went on, the lists grew longer.

By March 1971 there had been a death. A full year had elapsed between the date this woman's punch biopsy had shown CIS and the date she was brought back for a more extensive biopsy which showed invasive cancer. Despite a Wertheim hysterectomy where the internal organs are irradiated before the uterus, ovaries and upper vagina are removed, she died.

"It is very difficult," McIndoe wrote in a memo, "to maintain a high standard of reporting of the cytology work in such a climate. What can I say to a technician who misses an obviously malignant slide at the screening stage who replies, 'What difference does it make anyway, they are not going to take any notice of the result.'"

In 1971 the National Women's Hospital Tumour Panel was established with Bill McIndoe as convenor. It is not clear exactly who was responsible for the institution of the panel, but the purpose was to open up to discussion particular cases of gynaecological cancer.

By this stage McIndoe had been joined in his campaign by Dr Jock McLean, the chief pathologist at the hospital. McIndoe's unhappy role in colposcopying the same untreated women over and over again was matched by McLean's experience in the subterranean laboratories of National Women's.

Under the microscope he viewed thin slivers of tissue taken by biopsies and he was aware that he was viewing the same tumours in the same women over and over again. When he reported that the specimens showed CIS, or micro-invasion, or suspected invasive cancer, he was aware these alarming reports were not always acted upon. In other hospitals such reports would have resulted in prompt treatment.

In addition, there had been conflicts between McLean and Green about diagnoses from pathological specimens. Green would ask for particular slides to be brought to his room where he would sometimes write his own diagnosis beside McLean's, in spite of the fact that he was not a trained pathologist.

McLean calls cancer "an appalling enigma. Even 1.6% of the best treated females will develop another cancer. A woman who has CIS is at risk of developing something nasty. Positive cytology is a red light at a corner. Continuing positive cytology always requires treatment."

At National Women's the red light was not always being heeded.

McLean says that junior resident doctors came along to the Tumour Panel meetings to be entertained by hearing Green, McIndoe and McLean slugging it

out. Any staff member could come to these meetings and anyone could introduce cases. As far as McLean was concerned this was "progress". "It meant controversial cases could be brought out into the open and discussed. It protected the patients and ensured they could be treated in an orthodox manner. At one point one of the professorial people introduced an amendment that cases could not be introduced by the pathologist, only by clinical people, but it was defeated by a majority of the Hospital Medical Committee."

The Tumour Panel, however, was not a complete answer. Cases could only be discussed one at a time. It was, says McLean, "like Lord Shaftesbury. We could not get everyone out of the mines at once."

In 1973 McIndoe decided to take more formal action. Eight years had elapsed since the institution of the study and his attempts to prevent limited treatment of patients had met scant success. He wrote a memorandum to the medical superintendent, Dr Algar Warren, asking for "a reappraisal of policy" for cancer patients. There were women, he said, who because of "limited biopsies" were in danger of having hidden invasive cancer go untreated. He outlined seven cases to

illustrate his point.

McLean's accompanying memorandum to the superintendent outlined 14 cases where limited treatment, he said, was "not soundly based". All the women were eventually shown to have invasive cancer. McLean contended they had probably had it from the beginning, but because of inadequate biopsies, it had been missed. "In my opinion," he concluded, "these patients have had what can be termed varying degrees of delayed and inadequate treatment for a disease [invasive carcinoma] that is generally considered to warrant urgent hospital admission for adequate diagnosis and definitive treatment."

For instance, in one patient's case, McLean talked about inadequate diagnosis and "excessive delay". CIS was diagnosed in October 1967, but she received no treatment until six months later when a cone biopsy showed micro-invasion with possible invasive cancer nearby. More than two years elapsed before this woman had a Wertheim hysterectomy for invasive cancer of the cervix and vagina.

In another patient the biopsy showed CIS but possibly invasive cancer. No action was taken for a year when another biopsy showed invasion. McLean called

this "an example of delay in definitive diagnosis and treatment through failure to heed the warning of the possibility of invasive cancer in the initial biopsy."

In his reply, Green insisted that other clinicians were also following his mode of treatment and that other staff were implicated in the policy of limited treatment. He said that by studying the natural history of the disease "a calculated risk that invasive cancer could be overlooked" was always present, but he denied that delayed treatment affected survival rates. For early invasive cancers, he said the 10-year survival rate was 96%, so that patients whose cancers were "overlooked or treatment delayed" were not "at a disadvantage".

He cast aspersions on the quality of colposcopy and pathology and complained that McLean kept "the best diagnostic slides from many cases in his own private collection under a disease index only" preventing him from having access to them.

He regretted that "Dr McIndoe's indecision and doubt could cost a long lead in the elucidation of the problem of the natural history of in situ cancer".

Dissatisfied with Green's response, McLean and McIndoe again approached the superintendent with McIndoe listing

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100 women whose cases were causing him concern, and McLean concluding with a clear statement of the issues at stake for the women: "When patients are admitted to a public hospital they put themselves in the hands of medical staff with the explicit understanding that they will be provided with at least adequate, and preferably optimal treatment for their complaint. Clinical studies and trials to establish optimal management are at times necessary. However, when in the course of a trial it becomes apparent that patients are at risk, there must be a reappraisal of the trial".

"Despite what Professor Green may say, the consensus of opinion at present is that any delay in the diagnosis and treatment of invasive carcinoma puts the patient at an increased risk. A survival rate of 96% for Stage 1a carcinoma of the cervix is very good at a statistical level — but not for the four or so women who die from the disease. At our present state of knowledge no one can deny that there is every possibility that with earlier diagnosis and treatment, these four or so patients could be alive."

By this stage Warren too had become concerned. With him, McLean and McIndoe attempted to take their complaint outside the hospital to the controlling authority. They approached the medical superintendent-in-chief of the hospital board, Fred Moody, who discussed it with the board's chief executive. Despite the fact that the complaint came from a medical superintendent and two such senior doctors, Moody declined to act.

"The whole thing," remembers McLean, "was thrown back to the hospital to sort out."

The Hospital Medical Committee set up an investigation committee of three senior gynaecologists, chaired by Dr Richard Seddon (now professor at Otago Medical School). The resulting report, issued in 1976, vindicated the policy of conservative treatment: "It is the firm opinion of this committee that all staff members involved in the implementation of the policy concerned with this conservative management of carcinoma in situ have acted with personal and professional integrity."

The 1971 death which had so concerned McIndoe and which had intensified his efforts was put down by the committee to a "colposcopic miss", the responsibility for which, of course, lay with McIndoe.

By this time even Algar Warren who had been initially reluctant to act, was calling the report a "whitewash".

The unease was spreading, and more doctors were coming to see the validity

of McLean and McIndoe's views. Dr Bruce Grieve, a member of the HMC, supported further investigation and suggested that McIndoe and McLean give reports to the HMC. As time passed, says McLean, "the better was our case. More and more ladies were coming back with invasive cancer because of the conservative treatment while Green was going on with his mode of management. Doctors stopped transferring patients and Herb's reservoir of cases diminished."

The dangers McIndoe saw were twofold. First, by limiting diagnosis biopsies, a smouldering invasive cancer could be missed. Second, that by delaying treatment of not completely removing abnormalities, risks were being taken with women's lives.

Despite McLean's belief that their objectives had been achieved, in all the interviews we conducted in the course of writing this article no one could give us an assurance that the experiment ever ended. It was never formally stopped. No instructions were issued to doctors to abandon practices which by now had been shown to be dangerous.

Dr Gabrielle Collison, who came to the hospital as medical superintendent in 1983, in answer to our questions referred us to Professor Bonham who as chairman of the HMC, then the Ethics Committee, and head of the Post Graduate School throughout this time, had ultimate responsibility.

It is very difficult to discuss the National Women's Hospital experiment with Bonham because he does not concede that it ever took place. Despite the consensus we encountered with other interviewees that this experiment was to study the natural history of CIS, and despite Green's documented assertion in paper after paper and in memos which went through Bonham's hands that that was what he was trying to follow, Bonham insists that the subject of the study was quite different.

We must refer here to a problem we encountered in interviewing Bonham which made clarifying his views difficult. He has a tendency towards circumlocution. Several viewpoints can be contained in the same answer to a question. To take an example. When we asked if in some patients "there had been a deliberate leaving of part of the lesion, the excision of only part of the lesion", Bonham replied: "No, no, no, not

deliberate at all. Not deliberate leaving of it, that sounds, that's misinterpretation. They were taking enough to biopsy. We could call it a deliberate leaving if you like."

About one thing Bonham is clear. He insists that the experiment was not to study the natural history of the disease. It was, he says, to study "colposcopic control", "to treat the patients by minimum interference so long as the colposcopic control was adequate".

In 1966, he says, "it was suggested that it was time we treated people with either less than a hysterectomy or a full cone biopsy. And the offer came from Dr McIndoe that he would be willing to provide colposcopy."

It was McIndoe's offer, says Bonham, which made the experiment possible. "The theory was at the time that you could adequately follow it [the disease] with colposcopy. That was McIndoe's theory."

It is certainly true that McIndoe did not oppose Green's plan as strenuously in 1966 as he did a few years later when he could see starkly the reality of its consequences. Nevertheless only a very imaginative interpretation of events could claim that the experiment was to test a theory held by Bill McIndoe.

Where others define colposcopy as a diagnostic tool, Bonham refers to its use as "treatment". Of course, if colposcopy is "treatment", then it is not possible to claim that no patient went "untreated", for all had colposcopic examinations.

McIndoe, says Bonham, "could have gone on biopsying until he had taken all the abnormality", an absurd proposition, for they were not his patients and he was known to abhor the practice of some clinicians overseas who subjected women to a great number of biopsies without anaesthetic.

In fact, McIndoe objected to his role in the experiment from the start. In 1966, he wrote: "... inadequate tissue diagnosis, which can be the only description of the type of biopsy I at present perform (if this is to be the only biopsy done) and follow-up only taking the further steps if there is clinical or colposcopic evidence of invasion, would seem to me the type of care that should not be followed... If Professor Green's proposal is accepted I would feel it very difficult to take seriously any cytology reporting or colposcopic assessment."

Although McIndoe was clearly unhappy about the limited colposcopically directed biopsies Green expected him to do, Bonham still blames him and not Green for the 1971 death of a woman in the study. "I had the notes out on that one... and I am sure that one case that