INQUIRY INTO OFF-PROTOCOL PRESCRIBING OF CHEMOTHERAPY IN NSW

Name: Name suppressed

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OFF PROTOCOL CHEMOTHERAPY PRESCRIBING SUBMISSION OF

BACKGROUND

was born in England on 1947. He died of renal cell carcinoma on 4 March

2000. was a chemist with experience in metallurgy, food technology and the minerals

industry.

I married in 1975. We had two daughters, and

HISTORY OF ILLNESS

Dr was treating urologist at St Vincents Hospital in Darlinghurst. He removed kidney in March 1998. When cancer was confirmed after the operation he referred to John Grygiel for oncology care. attended two consultations with John Grygiel.

GRYGIEL MEETING 1

The first consultation took place around April/May 1998. attended by himself.

When came back home he told me the following: He arrived on time but was kept waiting. After a while a man walked out of the consulting rooms. Soon after John Grygiel took into the room. He told that he shouldn't tell him this but the man who had just walked had been expected to die of lung cancer some years ago. The man survived however and now only came in annually for routine checks. The man had been free o f cancer again at today's meeting.

was impressed and felt that he would receive good care.

GRYGIEL MEETING 2

The next consultation occurred around July/August 1998. A follow up CAT scan had shown liver metastases. I accompanied to this consultation. The event was so disquieting that I still remember it to this day.

John Grygiel greeted us in a cold manner, and took us in to his desk. He then took the scans over to a screen on the wall. He looked at the images and without coming back to his desk stated bluntly "It's inoperable". asked if surgery would help and John Grygiel said "No".

John Grygiel then went on to say: "You might read about new therapies in use in America. We don't do that here. St Vincents specialises in HIV Aids, breast cancer, lung cancer and leukaemia. We don't have the funding to provide the treatment you might read about. You are asymptomatic at the moment but that will change. When you become unwell some back to see us. We will make you comfortable". We soon found that he was referring to Interferon therapy.

There was nothing else to say so we left.

I complained to my GP about the meeting. She told me it was the right of any patient who was not satisfied with their treating doctor to go elsewhere. She arranged a referral to Associate Professor at RPA. Within a week received Interferon therapy without hesitation or

reference to cost. continued to receive oncology services from RPA until he died 18 moths later.

and I believed that the treatment he received at RPA successfully gave him a chance to extend his life. Similar options were not offered by John Grygiel.

ISSUES FOR CONSIDERATION

- 1. was not under-dosed. He was denied chemotherapy treatment that he was readily able to receive elsewhere.
- 2. John Grygiel's demeanour was aloof and without compassion. We interpreted his comments as saying: "You have a cancer we are not interested in treating. You are going to die anyway, so we won't waste any money actively treating your cancer. We wish to spare our resources for those patients we think might survive or be of special interest. Bad luck". was devastated by the brutality of the comments, and was relieved not to be treated further by him.
- 3. was not given any advice about how he could receive the treatment elsewhere. We weren't told the treatment involved Interferon, or any other information that might have helped as treatment. John Grygiel delivered his verdict with no opportunity for appeal. We weren't given an opportunity to even "pay our way" by purchasing Interferon privately.
- 4. We were grateful and happy to receive treatment to RPA. We believed it extended life. However as a very sick patient he had to travel across Sydney regularly to attend treatment and appointments. St Vincents Hospital is only five bus stops down Oxford Street. We lived in Paddington within easy walking distance to the Paddington Town Hall bus stop. His health and well-being would have been better served if the same treatment were available locally at St Vincents Hospital.
- 5. and I were realistic, and knew that he would die. However as a younger patient wanted to prolong his life to be with his children. He was a chemist who wanted to use his condition to contribute to research by going on drug trials. These options were given freely at RPH. However John Grygiel however simply "wrote him off". This is not the quality of care and compassion I had expected from St Vincents Hospital.

THANK YOU for the opportunity to contribute to the Inquiry. I hope this helps improve the standard of care all cancer patients receive in future.