

Dear Mr.Feinmann,

I am responding to the ACD of 30th July 2008. My comments are as follows :

### **Relevant Evidence**

**The evidence of the 3 "patient experts " has been ignored . In their submissions and at the appraisal meeting the patient experts were given almost no opportunity to state their views about their experience of RCC and their opinions about the treatments under review. Their experience of the process was that the NICE committee failed to involve them in the discussions and did not explore or attempt to elicit relevant and important information about the patient and carer evidence on the devastating impact of RCC .**

In a 4 hour meeting ,the patient experts were asked no questions by the NICE committee and were restricted to single statements which were curtly dealt with by the Chairman , Professor Stevens. These points are now the subject of a separate formal complaint .

### **Summaries of Cost and Clinical Effectiveness**

**The evidence was presented in a highly technical manner with no concessions made to involve the "patient experts" and with no attempt to explain the complex and academic debate about statistical method and health economics . The debate as such was limited to a discussion of the interpretation of data and in a style more suited to an academic common-room. It is worth noting that some of the data and method of some of the drug companies was challenged and yet they were not present to defend their work which is both unfair to them and confusing to the "patient experts " who were confronted with evidence which was contradictory and open to very different interpretation.**

The information and conclusions presented requires robust and rigorous challenge to ensure the method and the data analysis meets the highest standards. Regrettably the appraisal process was fatally flawed as the necessary expertise was not available--either on the NICE committee or among the patient experts-- to discuss and debate the statistical and methodological issues involved.

### **Provisional Recommendations**

**It was inevitable that all the treatments investigated would fail the NICE evaluation process for one simple reason . All new cancer drugs are by their nature expensive in view of their long development time . None of these drugs could ever meet the QALY set by NICE nor the willingness to pay level set at £30000. It is a cruel deception to evaluate drugs and treatments which are bound to fail the arbitrary tests set by Department of Health**

RCC is a cancer which responds very poorly to standard chemotherapy and radiotherapy. It is not a rare cancer with over 6000 cases per annum in the U.K. and with a rising incidence . The standard NHS approved treatments of interferon or interleukin have largely been discontinued in all other modern states as ineffective and in the light of these newer and more clinically effective drugs, unethical . It is recognised in the report that the data is immature but positive in terms of clinical effectiveness for all of these treatments . What does it say about our NHS if the only treatment supported by NICE for RCC is regarded by the rest of the World as unethical ?

### **Equality Issues**

**Current treatments for RCC are determined by the perfect postcode lottery . PCT's are individually deciding whether or not to fund these drug treatments based on the recommendations of their Appeals procedures each with different rules and criteria. This leads to a cruel and exhausting paperchase for patients as they seek treatments prescribed by their clinicians. This analysis does not take into account the quite different systems and outcomes in Scotland Wales and Northern Ireland. It will be a supreme irony if the results of this ACD are to COMPLETELY deny ALL the new and more effective drugs for RCC in England and Wales.**

If that is the outcome of this appraisal then NICE can be content that the theoretical equality outcome has been perfect-- no-one gets any of the more effective drugs on the NHS !

**I look forward to an early reply to these comments**

**Yours etc.**

**Bill Savage**