

LIVING WITH CARCINOID

Notes from 3rd Annual Meeting held at Holiday Inn, Birmingham Airport 20 March 2005

50 supporters present – apologies from Anna Jameson (Belfast)

Peter Gwilliam opened meeting by introducing Martyn Caplin and Cathy Bouvier (Royal Free, London), together with Carole Way (West Midlands) and Roy Craft (Devon) who have offered to assist in developing the support group.

Progress of website – Peter apologised for not progressing this further, but information had to be pulled together and it was hoped this would soon be achievable. Other sites which have significantly improved and warrant a visit are:

www.carcinoid.org

www.carcinoidinfo.info (Susan Anderson's new site)

www.netumoradvisor.org

there are several other American sites which are extremely helpful.

(If anyone has any helpful information which could be attached to the proposed website, or you have any views on what you would like to see on it, please contact Peter on peter.gwilliam@lineone.net)

The aim of this meeting is hopefully to introduce fellow patients and supporters in your area so you may wish to keep in touch locally. Peter thanked those who made financial contributions at the meeting which will help towards such costs as holding meetings.

Martyn Caplin gave his presentation on neuroendocrine tumours (NETs), the main points arising were:

- 1,500 to 2,000 patients diagnosed each year in the UK with a NET.
- Due to their slow growth there are probably thousands of patients throughout UK.
- Hormones produced by NETs can cause flushing, diarrhoea and low sugar.
- NETs have receptors which can grab the chemical circulating, binding it to the tumour which stimulates the release of hormones and peptides.
- Classified according to:
 - site of origin – ie pancreas, small bowel etc
 - whether they are functional (producing hormones) or non-functional (no noticeable symptoms) – although blood tests can reveal high levels of certain hormones in the latter

then subdivided into:

- well-differentiated (look normal) and poorly differentiated (abnormal).

Understanding will be determined by the biology of the tumour and the type of treatment the patient should have.

CARCINOID TUMOURS

- When first looked at autopsies in the whole population 20-30 years ago, it was found that 1% of the population had a carcinoid tumour without realising it, proving that they are normally indolent and only a sub-set become more active, which usually occur in the foregut 20-30% (bronchus and stomach), midgut 50% (small bowel and appendix) and the hindgut 20% (rectum and colon).
- Rarely associated with genetic conditions and not usually hereditary, but can occasionally be associated with other cancers such as bowel cancer. Recommends that patients with carcinoid tumours should have some form of imaging of their large bowel especially to exclude polyps etc developing.
- Proportion of patients may have the carcinoid syndrome – flushing (90%) – with maybe palpitations, diarrhoea (70% of patients), abdominal pain (40%), wheezing (15%), heart disease (30%) and skin problems (5%). A number of different chemicals can be associated with each of these features - this sometimes makes it difficult to treat.
- Disease more frequently diagnosed nowadays – increase in rectum and gastric carcinoids but decrease in appendix.

- A USA survey covering about 10% of the population compared results from 1969-71 - the number of new diagnoses has virtually doubled in the white population from 1.3 to 2.5 cases per 100,000, but in the black population it is twice as prevalent. Further studies now being undertaken.
- Not all patients who flush have a carcinoid syndrome – may be another type of NET.

PANCREATIC NETs

- Produce characteristic markers. Islet cell type tumours – include
 - gastrinomas (recurrent peptic ulcers, diarrhoea, abdominal pain)
 - insulinoma (low sugar, faints, sweats)
 - VIPoma (diarrhoea, flushing)
 - Glucagonoma (high sugar, rash)
 - Non-functional – most common - (jaundice, mass in abdomen).
- Often when patients present, they may already have had spread to the liver.
- 10-25% have an associated genetic condition therefore need to consider family screening.

The most common type of hereditary condition is one called Multiple Endocrine Neoplasia Type 1 (MEN-1) where there is an overactivity of the parathyroid gland in neck in 90% of patients. The pituitary gland may develop a benign growth resulting in over-secretion of pituitary hormones. 30-70% of patients with MEN-1 will have pancreatic endocrine tumours – rather than 10% having carcinoid. In 1997 the gene was discovered for the condition, so now there is genetic testing available. The gene itself makes a chemical which stops the cells over-replicating. When the gene malfunctions and the cells become more active they turn into tumours.

NETs

Although similar in cell type, investigation and treatment options, each tumour type has a different biology and prognosis outlook. All NETs were previously lumped together and called carcinoid tumours, even if it was an islet cell tumour. Patients are now managed individually and it is important to understand that individual's tumour biology and the effect on that patient.

- NETs can be diagnosed by:
 - Serendipity, chance – investigation following local symptoms of discomfort in the abdomen and diarrhoea may result in biopsy of a cancer which is then found to be a NET – also on further investigation of reported flushing, fainting episodes, low sugar.
 - Pancreatic tumours – sometimes told they have pancreatic cancer but on biopsy they are found to be a NET, so different treatment strategy is required.
 - Patient may present with many non-specific symptoms and the so the median time to diagnose a patient with NET is still in the region of 5-7 years – far too long.

Teaching programmes being set up for junior doctors to think of NETs. Diagnosis at an earlier stage gives a better chance of cure.

IMAGING

Many types of imaging undertaken:

- Ultrasound – pretty coarse measurement, has low sensitivity in trying to pick up and identify the primary tumour, but is good in identifying lesions in the liver.
- Spiral CT vs MRI – CT diagnostic capability has significantly increased and both can detect the primary tumour in around 70% of patients and most of the areas of tumour spread in 90%. Injecting a dye will improve the imaging.
- Octreotide scan – key test for NET patients. Based on the chemical binding to the receptor on the tumour surface and lighting up as a hot spot. Quite good at detecting the primary site but most sensitive to determine where the tumours have spread.
- Endoscopic Ultrasound – one swallows the endoscope which has an ultrasound probe and this is very good at assessing stomach polyps and NETs and can also assess tumours within the pancreas, especially if one is going to be considering surgery. Also used for rectal NETs.
- Angiography – not so often used. Dye is injected into the groin to determine where small tumours are within the pancreas. Because of the advent of the endoscopic ultrasound, angiography isn't used so much as it is much more invasive.
- Intraoperative Ultrasound – at the time of an operation the surgeon or radiologist will be in theatre with the intraoperative ultrasound trying to locate tumours more accurately for the surgeon to remove all the tumour or additional tumours that may be hiding.

Several images were then displayed of various images. It takes several years of experience for a radiologist to interpret scans.

SYMPTOMATIC THERAPY

- Octreotide (Somatostatin) binds to the tumour cell and the binding can block the release of the peptide which can block the symptoms from the hormone and slow down tumour growth. The body produces a small amount of the hormone somatostatin which only last 2-3 minutes in the circulation and this natural hormone inhibits the release of the chemicals causing the carcinoid syndrome or the hormones released from the pancreas causing acid secretion. Novartis developed Sandostatin/Octreotide and subsequently Ipsen developed Lanreotide. Using these as injections last hours in the body rather than a couple of minutes for the natural peptide. Can also inhibit the hormones which cause flushing and diarrhoea. As an anti-tumour agent it will only shrink tumours in around 8% of patients, although the latest statistics in terms of stabilising tumours, so they neither grow nor shrink, show about 50% of patients will benefit.
- For the pancreatic type of NET, again Octreotide and Lanreotide have been shown to reduce the hormone levels in the different types of NET and also subsequently improved the symptoms. A few patients have had reduction in tumour size but many will have had stabilisation.
- Somatostatin Analogues – Octreotide can be given as a subcutaneous injection – the original short acting formulation was given in varying doses of 50-500mcg 2/3 times a day. Novartis then developed the long acting, once monthly, preparation and Ipsen developed the 2-weekly preparation which has now been extended to monthly. These are known as Sandostatin LAR and Lanreotide Autogel. Similar efficacy between the two although the Autogel is newer so less data available. Both have large needles! Big issue has been over funding for the once monthly treatment.

DEFINITIVE TREATMENT

- Surgery – removal of tumour is the only real chance of cure. The surgical considerations themselves have changed over the last 5 years. It is possible that the primary tumour will be removed from the pancreas, intestine or lung and at a later date have resection of the tumours in the liver if feasibly possible and if the patient is up to it.
- Debulking – surgical procedure to try and remove most of the tumour but may still leave some behind and that's a consideration if it is a very active hormone secreting tumour. Part removal of the bulk may then reduce the secretions and give a better chance of other treatments to work.
- Liver transplant – very rare for NETs. If to be considered, the disease has to be confined only to the liver and there has to be no evidence of tumour outside. In transplant patients there has been an early rate of tumour recurrence which can be more aggressive.

NON-SURGICAL THERAPIES

- Interferon – which may or may not be given in combination with Octreotide. Interferon is an injection which stimulates the immune system to fight cancer cells. There's a formulation with the standard Alpha-Interferon injection which is given subcutaneously just under the skin, often 3 times a week. There is a once weekly form of pegylated Interferon, which is a lot more expensive than the thrice weekly injection. Problem with Interferon is the side effect of patients who often suffer flu-like symptoms and up to 50% of patients can have depression. If patients are showing benefits of being on Interferon then they can be on it for many years without too much in the way of side effects. It is not appropriate for all NETs and one has to be quite selective in defining which patients should be on the therapy.
- Chemotherapy – many NETs are resistant to chemotherapy, especially those originating in the small bowel and colon. However, chemotherapy may well be appropriate for tumours derived from the foregut (lung, stomach and pancreas) with shrinking in about 40-60% of patients using a specific combination of chemotherapy agents, usually based around Streptozocin (STZ), 5 Fluorouracil (5FU), plus or minus a drug called Adriamycin (ADR) plus or minus a drug called Cisplatin. With new drugs one can abrogate some of the worst side effects in terms of nausea and vomiting. One patient who had a large pancreatic tumour, invading the main vein, undertook chemotherapy and the tumour shrunk enabling the surgeon to remove the tumour plus the spleen. This patient is still tumour free after 3-4 years.
- Embolisation – this cuts off the blood supply to tumours in the liver. A small catheter is fed in through the groin into the artery that's feeding the tumour and then some particles are put into the artery which blocks off the blood supply to the tumour so it shrinks. At the same time, some patients may be injected with chemotherapy as

well. It has been proven to have symptomatic and survival benefit in patients with NETs, but the downside is patients will often have upper abdominal pain, nausea and fever for the first couple of days after the procedure and many will feel like they have been kicked in the abdomen for a couple of weeks.

- Other ablation techniques – radio-frequency ablation (putting a probe in to burn tumours), microwave ablation, laser ablation, cryoablation (freezing the tumour) and ethanol ablation (simple alcohol injection into small sized tumours). Some good results especially from the radio-frequency ablation, but as with all procedures there are always side effects which need to be discussed with the doctor.
- “Magic Bullet” – radionuclide targeted therapy. This is where the most advance has been in the last few years. If a label can light up hot spots, the dye can be swapped with a stronger radioactive agent which will attach to the receptor with a good chance of shrinking tumours all over the body. There is a range of radioactive substances: I-131mIBG (been around for about 20 years) / Yttrium-90 Dota Octreotide / Lutetium-177 Octreotate. Very well tolerated procedure, but because of the radioactivity, patients need to be in hospital for 3-4 days and subsequently blood count and renal function needs to be kept under review.

SUMMARY

Doctors have to have a high index of suspicion for suspecting a patient with a NET. Patients should have the appropriate biochemistry, the appropriate blood test which should include testing the level of Chromogranin A, and the 24 hour urine 5-HIAA test which is often elevated in patients with carcinoid tumours. Also check for other chemicals which could be elevated. Patients often first have an ultrasound scan as a quick way of identifying tumours within the liver - the most sensitive method is the CT or MRI scan in terms of the 3-dimensional aspect. All patients who have metastases (spread of tumour), or when a tumour is identified on a CT scan, should undergo an octreotide scan, as this is the most sensitive scan for picking up small tumours elsewhere. One has to consider whether patients have an hereditary component to their disease. Patients with gastrin secreting tumours, causing recurrent peptic ulceration, should have an endoscopy to find out how much ulceration has arisen. We may do an endoscopic ultrasound to try and identify further the tumour in the pancreas. For insulin secreting NETs, we will try to locate the tumour more accurately with the endoscopic ultrasound. We may rarely use the angiography to look at the blood supply of tumours in the pancreas. For other types – pancreatic, gastric, rectal NETs – we may also look at endoscopic ultrasound to identify those tumours and the depth of invasion of the tumour beneath the surface and to see if they're invading into other organs. In addition to the CT, MRI or octreotide scans, we may perform an oral barium dye test to pick up small intestinal tumours. Patients may also have an mIBG scan. There's a new imaging technique called PET imaging available in most large hospitals, but the standard PET imaging is often negative for patients with NETs. New agents called 5-HTP PET and dopaPET, which the German and Swedish groups have been working on, look very exciting in terms of being more sensitive than the octreotide scan. The key to managing patients is understanding the histology of the biopsy in order to predict what's best for that patient.

We may consider a trial of the drug octreotide to stabilise the tumour. Patients will often enter into observation protocols and may, initially, if they have tumours which suggest a very slow growing type, not have any treatment but will be scanned every 3-4 months so if the tumours start to grow, then that's the time to treat the patient. We have a choice of chemotherapy, especially for the more aggressive types of pancreatic NETs. For disease that is mainly confined to the liver, one rarely considers liver transplant, but perhaps now more frequently we are considering liver surgery. There is also embolisation, various ablation therapies, magic bullet treatment. There are some exciting new drug developments over the coming year and a number of patients may enter into new drug trials as well.

Within the UK we have set up the UK NETWORK Committee and many hospitals are now represented. The idea is that there should be experts available in different regions throughout the UK. Guidelines are due to be published and available for all doctors within the next 2 months. Scientific and clinical collaborations throughout UK as well as with the European Neuroendocrine Tumour Society. Annual national conference now held. The Committee will also work closely with patient support groups to get feedback from patients.

Question & Answer Session with Martyn Caplin

Q: *Due to length of time for junior doctors to become GPs, is there any way GPs can be made more aware of symptoms/diagnosis and not just to think of IBS?*

MC: A GP practice may only see one patient with carcinoid tumours within their 2,000-3,000 patients. 50% of the population are said to have IBS and it is therefore difficult to decide who to screen further. Even when the patient has been diagnosed, difficulties may still occur as to treatment and drugs. As soon as we are aware of newly diagnosed patient, a video and patient pack, produced in co-ordination with Ipsen, are sent to GP and patient to help understand disease (patient packs can be obtained by telephoning 01753 627777 or e-mailing medical.information.uk@ipsen.com). Novartis has also produced an educational resource. Cathy Bouvier has written articles for nursing journals and some key pharmacology journals that GPs tend to read, but as the likelihood of them coming across the disease they may not take it in! The Christmas Appeal a few years ago in the paper raised general awareness. Martyn has taken on the Directorship of the National Electronic Library for Health for gastroenterology and hepatology and its aim in the next 5-10 years is to key into all doctors electronic information, so that if someone comes in with a diagnosis of diarrhoea, then certain things will flash up saying "Have you considered?" then listing relevant diseases for consideration.

Q: *What should one do if there has been no onward referral to an NET specialist?*

MC: Hopefully the Living with Carcinoid website will list all the key sites in the country where there is a specialist in NETs. Most of the country is now covered. Within the Cancer Network hospitals, patients should be able to ask who is the lead specialist for NETs within the Cancer Network. If not one in local region ask to be referred to one in adjoining area.

Q: *After being diagnosed 4 years ago, went to local GP who said he wasn't up on carcinoid and on re-visiting GP mentioned it again, but he still said he wasn't too well up on it. Is this a new disease?*

MC: This was primarily why the local groups were set up to educate doctors. 5-10 years ago the original approach was not to do anything for these tumours, but with better understanding of individual types of NETs, management is now more active with different therapeutic strategies available. Carcinoid tumours have been known about for over 100 years.

Further comments from floor:

- Problems trying to get past original consultant to be referred to a specialist
- Patients now have to push for what they are entitled to and insist on seeing the correct specialist

Q: *For a future meeting, would it be possible to split attendees into types of complaint so that comparisons can be made with other patients?*

PG: This will be considered.

Q: *Is Sandostatin better than Interferon?*

MC: They are totally different. Sandostatin reduces hormone secretion by the tumour cells. Interferon does that as well but may have more anti-tumour effect. There are more side-effects with an Interferon type drug.

Q: *Is it common to support Sandostatin LAR with antihistamine treatment in respect of flushing?*

MC: No. Antihistamine was used 20-30 years ago and showed some benefit in a proportion of patients. Where symptoms are mild, this may still be considered. Side-effects can make patient feel sleepy.

Q: *If hereditary, what other family members would be considered?*

MC: New patients would be asked about parents, grandparents, brothers/sisters, children and if any had unusual cancers, a NET, parathyroid problem then notes are placed on their record. Discuss pros and cons of genetic testing. Not carried out as a matter of course as outcome could affect insurance policies etc and patients even penalised for having a genetic test.

Anna: The moratorium for insurance companies being able to request information about genetic testing has been extended to 2011.

- Q:** *Do you find any common side effects from either LAR, short term Sandostatin or Interferon?*
- MC:** Common side effects can be nodules forming at injection site with irritation. May also experience griping abdominal discomfort, worsening diarrhoea related to Octreotide or Sandostatin as the pancreatic enzymes don't work as well. Longer term effects – 50% of patients on Octreotide or Lanreotide will develop gallstones, out of which only 10% will become symptomatic. Now suggesting to surgeons that anyone having an operation for a NET, they may consider taking out the gallbladder at the time of surgery, so in future years they may save another operation to remove it.
More side effects with Interferon similar to flu symptoms and depression which can be quite debilitating. Checks required on blood count as white count, which fights infection, can be suppressed, a number of patients can become anaemic and problems may occur with clotting. Also check for thyroid gland problems regularly, problems with joints, and intolerance of Interferon.
- Q:** *Do you think it could cause diabetes and other diseases?*
- MC:** It is possible – not quite so recognised with Interferon.
- Q:** *Are there any results from the Sandostatin questionnaires sent out?*
- CB:** Still awaiting outcome. The presentation of the pack was changed.
- John:** Now finding there is a gap between injections.
- MC:** Shouldn't be any change in the chemical formulation and the treatment effect. Nurses seem to prefer the new package.
- Q:** *With long-term chemotherapy do you have any data on length of treatments, for example I have chemo for 5 days, is there any reason why it couldn't be 4 or 3 days?*
- MC:** Depends on which chemotherapy agent is used. Strategies are changing – appears to be benefit from giving certain agents on a more consistent basis rather than the old-fashioned bolus basis, where they'd have the one bolus and return the next month. With the 5-fluorouracil agent, which used to be given as a bolus then an infusion over a week, there's now an oral agent, some patients taking daily or for 7 days in a month. Appears to be more benefit if taken over a period of a number of days, but it is agent specific. National trial being undertaken with NET patients looking at chemotherapy, where we used to give the intravenous 5-FU as a bolus and then switching it over to the oral capecitabine preparation.
- Q:** *One of the symptoms on Martyn's presentation was pellagra (5%), what is the approach to manage it?*
- MC:** Probably under-diagnosed. Many patients with carcinoid syndrome will have dry skin and irritation relating to Vitamin B and niacin deficiency. Many of my patients are on a strong compound Vitamin B supplement, which has niacin or nicotinamide supplement, and with an appropriate amount pellagra should be overcome.
- Q:** *My wife gets a reaction to taking the niacin, is there anything that can be done for that?*
- MC:** There are various brands of nicotinamide that can be tried. Some patients have been given an intravenous supplement, so there are some ways around giving it.
- Q:** *Is it advisable for everyone who has carcinoid to be on Vitamin B?*
- MC:** If you have the carcinoid syndrome, then there are definite benefits to being on Vitamin B as the body does become deplete because the tumour cells eat up the Vitamin B which then results in conditions such as pellagra. Also think there is also a benefit of having a broad spectrum diet in terms of Vitamins A, C and E because they are scavengers in terms of mopping up inflammation as well.
- Q:** *How big is the support group now?*
- PG:** There are now just over 200 on the database who were all notified of the meeting, together with fliers to specialist groups.
- Q:** *Regarding the Chromogranin A, is it the trends that are more important than the actual numbers?*

MC: Chromogranin A is a chemical which is released by most NETs and the blood test is the best marker for following them. The chemical helps package the hormones within the cells and the Chromogranin is released when the hormones are released by the tumour cells. It is present in around 90% of NET patients. The clinician will follow the pattern of the Chromogranin A in that patient, so if we see it rising each time you know the tumour is becoming more active. It is sometimes found to be a prelude to the actual tumour changing in size, so the tumour cells may become more active, yet the CT scan doesn't change. Also a useful marker following therapy to see whether there is a change in the size of tumour in terms of the CT scan or a fall in the hormone levels, or remaining the same where a patient has a static disease. One of the key benefits of the UK Group now is that every time a patient has a gut hormone profile sent off, the Chromogranin A is automatically measured and is now available throughout the UK. Every UK patient now gets the same assay for the measurement of their Chromogranin A, the north half of the UK is sent to Belfast and the south half goes to the Hammersmith, both using the DAKO assay. The two labs also look at other hormones and they are able to use it for research to compare with the standardised DAKO.

Q: ***What is considered to be the normal level of Chromogranin A?***

MC: The lab level is less than 60, but patients can have levels of 500 who are awfully well. This can be related to the amount of tumour that an individual patient has, so a patient may have a level of 500, have quite a high distribution of tumour, but because the tumour is staying fairly stagnant they will have a constant level of 500. One hopes to bring the level down with octreotide; however the trend is the key, but the starting point is often the level of tumour burden that the patient has. There is also Chromogranin B, but the A is more sensitive and therefore measured.

Q: ***Is it necessary for carcinoid patients to have an echosound every year?***

MC: Not necessarily every year. Patients who have primary carcinoid tumours associated with the small bowel or lung, and where there is the carcinoid syndrome, a proportion of patients (perhaps up to a third but not so many since the advent of octreotide) can have problems with the heart valves on the right side of the heart. Screening for those patients will also include an echocardiogram to scan the heart valve. We are aiming for all carcinoid patients to have a heart scan locally and it will then be up to that centre how often they are conducted. In the ideal world they would be done annually, but realistically within the NHS it is likely to be every 2-3 years.

Q: ***Is there any work being undertaken with regard to dietary requirements?***

MC: Richard Warner gives some advice on his website as to the management of carcinoid syndrome and his wife, Monica, is a nutritionist by training. There is a bit of information in our packs but we are looking at setting up a programme of research in terms of diet with our nutritionists. I have always been concerned that patients don't become too faddy, as it is important to maintain the weight to a large degree. Patients with pancreatic tumours often need to have a low fat diet. Other types may not need low fat diets. High protein in the diet is useful and also in terms of the more you can maintain protein levels in the body, it is useful for making other amino acids and proteins for fighting disease. Sugar balance for a diabetic patient must be kept under strict control.

CB: CancerBACUP have produced some good booklets in the last few months which also include recipes and where to obtain specialist supplements. The McMillan team also do a thick dietary book which is very good. Monica Warner's own website gives her dietary guidelines, but this was written in 2001.

Q: ***Could you say a bit more about the exciting new developments likely to arise in the next year or two?***

MC: Most of the developments are drug company driven, although a number of us have our own research programmes in terms of elucidating which new drugs would be most appropriate for patients with NETs. In terms of chemotherapy, there are some new anti-angiogenesis drugs which are currently in trials. These inhibit blood supply or blood growth by tumours – tumours need a blood supply to grow. NETs are very vascular tumours and have a high circulation to their local tumour area, so intuitively if you can inhibit that process, then that should be a good treatment for NETs. There are several anti-angiogenesis agents which have come out in the last year and are currently in clinical trial. It is now a question of trying to pick which agents are the most appropriate for patients with NETs. There are other new agents we are interested in – the epidermal

growth factor receptor antagonist – looking to target specific receptors on the surface of the tumours. These will be coming to trial over the next 12-24 months. In terms of the magic bullet targeted therapies and new agents, Lutetium 177 is the newest of the radioactive treatments which looks like it may well turn out to be superior to the Yttrium therapy in certain types of NETs. There are also new immuno therapies targeting the immune system where the immune system is working in a negative way. Plus there are some agents which are being developed for intravenous injections but these are in preliminary trial. Ultimately, 5 years down the line we could be looking at genetic targeting and we have just started a collaboration with one of the key groups in the States in looking at some genetic markers to see if it's a way forward in predicting the course of the tumour but also in trying to develop treatment in 5-10 years.

Q: *How are people brought into these trials?*

MC: The aim will be that trials will be advertised across the cancer networks, so people should be aware of those trials and where they are taking place. One of the aspects of the website should be keeping up-to-date with what trials are going to be developed so patients can be informed.

Q: *Regarding survival rates quoted on the web, what is the difference between cause specific and relative survival rates?*

MC: There are lots of different terminologies used and a lot of the literature for survival rates is actually quite old and pre-dates a lot of the new treatments. The survival time for patients with NETs is very variable and it can be quoted as short as, for patients with liver spread for certain types, 1 or 2 years. I'm always cautious about patients delving too deep into this, as one has to look at the individual scenario and treating that specific individual. Some of the statistics are going back to when there was one treatment – which obviously worked for some patients but not others. We would now look at the median survival, which is the survival of 50% of the group and what percentage would survive 5 years or 10 years, but it will take some years for that data to come through. The other factor is quality of life and the issue of specific questionnaires for patients with NETs to give an insight into the impact of treatments against their quality of life.

Q: *Following the Reading meeting last year, some insurance companies were recommended – has anyone had any response?*

CW: Having tried to obtain insurance recently, that broker (C H Facilities) no longer deals with Fortis and was unable to provide cover. However, I did obtain European annual insurance for me and spouse at £82 via another broker (JD Consultants & Medical Brokers – 01689 859102) - with Fortis!! The Post Office also use Fortis yet their screening questions excluded me and they refused cover. Screening questions seem to vary from broker to broker so it's worth persevering! Cancerbacup and Northern Cancer Network have a large list of different companies and brokers and it is probably a question of trying them until you find one that is suitable.

Others to try: Insure & Go (Family for 19 days in France £34) –
www.insureandgo.com/ContactUs.html - Tel: 0870 9013674

AXA Direct

Obtaining insurance seems to be more of a problem for the over 65s.

If you require the Novartis book called "NETs and their Treatment", which is quite useful, phone 01276 692255.

Details of other available literature will be emailed and added to the website.

Peter Gwilliam thanked Martyn Caplin and Cathy Bouvier for giving up their time to attend the meeting and it was much appreciated by all present.