

Road to Basel, A New Experience for me

Michael Neal and his wife Sherrie have written an excellent record of their experiences during PRRT in Basel. Please go to www.roadtobasel.com and read Michael's description first. What I have done here is to just add another perspective as I prepare for and conduct the trip myself as a patient in May and July, 2009.

Treatment Request

Baseline Requirements

My Diagnosis: Since each person displays their neuroendocrine cancer in various ways, here is my condition at the time just before PRRT treatment:

- 5.3x5x8 cm islet cell tumor on the pancreas head, mostly non-productive, displays some characteristics of a glucagonoma.
- Liver mets estimated to be causing a 10-15% tumor burden.
- No detected mets elsewhere.
- My most prominent symptoms are diarrhea and hyperglycemia.
- I am not taking Sandostatin which would complicate the PRRT process a little bit more.

I exhibit high affinity somatostatin receptors on the neuroendocrine cancer cells, as shown by the octreoscan. This feature and a relatively low liver tumor load are important factors and good predictors of the potential benefit of the PRRT.

As an aside, I take oral meds for high blood pressure, high cholesterol, and hyperglycemia.

Submitting the test results for qualification to Basel included:

- current CT scan (within the past 60 days)
- current octreoscan
- liver ultrasound
- bone marrow biopsy (see note)
- blood work, (CBC, tumor marker results, etc.)
- patient history
- letter from referring physician (if applicable)

Note: Since I had had four rounds of standard chemo previously, there was some possibility the Streptozocin could have left permanent damage to the bone marrow. Luckily, I had none. Additionally, the biopsy also checked to make sure I had no cancer cells in the marrow.

It took from December 17, 2008 until January 22, 2009 to complete the tests. On January 30 the packaged results had been assembled and sent via FedEx to Basel.

Receiving the Invitation

The invitation from Basel came via an email on February 25, 2009 from Brigit Avis, Assistant to Professor Dr. Jan Müller at the University of Basel Hospital. Brigit (Therapie-NUK@usb.ch) is the interface between you and Basel. (Her assistant is Christine Evard.) The invitation spelled out the proposed dates, the general schedule of all treatments planned (mine included two treatments, roughly 10 weeks apart), and the costs of each treatment (including forms of payment, i.e. credit card, cheque, cash, wire transfer). It included an attached information sheet on a few close by hotels and the University's hostel. Another attachment is an explanation of the disease and the PRRT treatment. (When you get to Basel, there is a place to sign this information sheet indicating an understanding of what is to be done.) You are required to respond and confirm this invitation indicating your ability to meet the appointed dates and inclusive costs.

Another .pdf file will then be sent asking for personal contact information, local doctors' names, and emergency contact. I printed this form, filled it out, and faxed it back to Brigit.

Treatment Costs

At the time of my treatments in May and July of 2009, the Y90 cost was 9,240 CHF. This breaks out to be

Hospitalization + routine scans cost:	1080 CHF for each of three days stay
PRRT injection cost:	6000 CHF (Y90 DOTATOC)
Total:	9240 CHF

Although as it turned out, I didn't get the Lu 177 treatment, it was quoted to me at 5200 CHF total cost.

This cost itemization may be helpful for filing an insurance claim. There are many if's and but's, but even if your insurance company denies the drug, because they say it is investigational/experimental, they may approve the hospital room and scans for coverage (the non-experimental parts). Medicare will not pay for any treatment/procedure outside the U.S. There is a slightly better chance of coverage if your insurance is self-funded by your employer. Good luck.

Planning the Travel

There are probably as many ways to travel overseas as there are modes of transport. My wife and I live near Kansas City. Here is what I recommend and/or did:

1. Get your passport(s) if you haven't done this already. Having this time consuming task done well ahead is one thing out of the way that may otherwise influence your ability to accept the dates of the invitation.
2. For the first treatment, we elected to arrive in Basel on Saturday, get settled, adjust the body clock, and tour a bit on Sunday before reporting for treatment on Monday morning. If the schedule works out as planned, I will be released about 11:00AM on Wednesday. The invitation suggests staying a few days more for rest before heading home. So, our plan was to leave Basel on following Saturday morning.
3. Using Expedia.com, I compared the cost of connections offered by several airlines. For us, we had to connect through Chicago, or Atlanta, or Dallas, or Detroit, depending on the airline. On the European side of the Atlantic, other stopovers would be London Heathrow, Paris, Frankfurt, Zurich, or Amsterdam on the way to Basel. (The regional airport for Basel – designator is BSL --- also serves Mulhouse, France, and Freiburg, Germany.)

I considered flying only to Frankfurt and taking the train from there to Basel. A one-way 2nd class train ticket costs about \$97.00. The added cost of flying all the way to Basel was nearly that same amount. So, we elected to fly all the way to Basel, which may have changed the European connecting airport for scheduling. Our routing was Kansas City-Chicago-London-Basel. It's a short taxi ride from BSL airport to Basel (approx. 35.50 CHF). Train and bus connections to Basel also abound. If you want to Google the Basel Europort and/or London Heathrow, you can find the airport layout for familiarization and match the layout with your airline arrival and departure terminals and gates. Probably the same research idea can be applied to other international airports.

4. The hotels in the Basel area can easily be checked just by Googling "Hotel Rochat". You will find references to all kinds of other hotels in the area. We chose the Hotel Rochat (the locals said to pronounce it Ro-sha) since it was closest to the hospital and available. I made the reservation on-line www.hotelrochat.com. The hotel promptly replied, and that was an easy task to accomplish. I know that if the treatment dates had been sooner or during a Swiss holiday, it may have been more difficult to reserve the Rochat room. The University hostel is the other closest place to stay and less costly than the Rochat. The hostel is a ten minute walk to the hospital entrance. Take your own supply of tissues. Your cell phone, computer, and camera battery chargers will probably work in Basel if you have a plug configuration

converter. Read the qualifiers on the chargers. They should say 110-240 v, 50-60 Hz.

Parking space at the Hotel Rochat is limited to four cars in a very tight area. I overheard it costs 25 CHF/day for this service. Street parking is nearly impossible. Public pay parking is available for the hospital and near to Marketplatz. Since the public transportation is so good and extensive, I'd recommend no rental cars. If you insist, it will be a hassle.

5. If you need to take a supply of special liquid drugs and accompanying paraphernalia, you must have a letter from your doctor in order to get all this stuff through airport security if they question you. No one ask to see my letter. After going through airport security without any cooling for your drugs, get some ice for the container. The airline people are used to being asked for ice to keep medications cool.

6. Take some Swiss Francs with you, at least a few hundred. Your local bank can probably make this currency exchange for you. Your credit card can also be used at the airport to get local money at an ATM, but it's probably cheaper to have this done before you leave home. Getting some native coin of the realm is a big help to avoid at least the initial problems of paying for a taxi and buying food and forgotten toiletries soon after you arrive. Make sure you know your credit card PIN before you find out you need to use it to obtain cash in a foreign country. You might also consider having a few euros in your pocket for miscellaneous purchases at the stopover airports. I like to call the credit card company ahead of travel, and have them note the expected card usage in cities where you are traveling. If you select to pay the hospital using a credit card, this will preclude any probable denial by the card company.

As indicated above, treatment payment can be accomplished in many ways. I chose to wire transfer the money. That way I could monitor the currency exchange rate fluctuations and time the payment for my advantage. A one percent advantage saves 70-80 dollars per thousand.

http://moneycentral.msn.com/detail/stock_quote?Symbol=%2fUSDCHF&FormatAs=Index

Food

1. Restaurants are everywhere. Find the Marketplatz and work your way out from there. The market is open every day except Sunday. Only once did we eat at a place where the waitress didn't speak English. She quickly brought over another person and there was no issue at all. Most people speak at least four languages. English is almost universal, as is French, German, and Swiss. Then sometimes you can add Spanish and Italian to their capabilities. How do they do it?
2. From the Hotel Rochat, you are very close to the Marketplatz. Step outside the hotel, make a left, after 30 paces turn left again at the corner of the hotel. That is the Peterskirkeplatz. After 50 yards, or so, there are 80 steps leading down to the market area. The hotel will provide a tram rail/bus map and a free visitor pass if you want to ride either conveyance. We did, all over the place. My wife preferred the steps on the right (south) side of Peters Kirke.
3. Food is more expensive than here in Kansas City, a little over twice the price. Unless you buy a sandwich at a vendor stand for 6-10 CHF, expect to pay 15-20 CHF per entrée for lunch and 17-30 CHF for a dinner entrée. A half-liter of water costs 4-6 CHF. All that adds up. The Hotel Rochat has a free breakfast and a great lunch for as low as 14 CHF and free water. Hotel Rochat doesn't serve dinner.
4. Tipping. The Swiss love Americans because we tip too much. A friend in Zurich says a typical tip that rounds up the bill to the next whole franc, or if it's a big bill over 60-70 CHF, add 2-3 percent as the tip. Boy, we made a waiter really happy before we learned this.

Notes from Michael Neal: (5/6/09)

What and when to eat before going in on Monday? They will suggest just a light breakfast of some type. Keep in mind that Rochat has great breakfast and they include eggs done to order (You have to ask for them.) which most of the places do not. You will find cereal, various breads, jelly, fruit, yogurts, juices, etc...it is great and included with your room rate.

What to take with me for the hospital stay? The hospital room has a TV and a radio as well as small headphones that plug into the TV as you might watch something other than what the person you are sharing the room with is watching. Keep in mind that English TV is scarce, only the BBC and an International News station, as well as MTV. One thing to note is that after 11 PM, you will find allot of porn style tv on the networks. They are mostly escorts and telephone sex ads but, I was shocked at what was on normal TV at night. The rooms have drinks, water, tea, coffee, etc...and you may request any drinks you want from the nurses on your floor (Pierre and Martin) they are great and speak very good English. They are big on you drinking Coke if sick and they provide it for free when you are being treated. They even have wine and beer.

Some folks take iPods, with them. I suggest you take something to read or do while in the hospital. They do not provide clothes to wear and most wear some type of sweat suit of the sort. Sherrie had jeans in the day and a short sleeved shirt as they need to place the IV in your arm. Your room is on an upper floor and you will ride the regular elevators to the basement for the treatment as well as the several times you have scans and x-rays. Some type of slip on shoes would be recommended. You will have to stay in your room the day of the treatment and you have a restroom and shower that you must use as it captures your waste water due to contamination, you are not permitted to use any other RR in the hospital.

You will have a phone in your room and can be called directly if you give the # to anyone here in the states. I suggest getting a cell card as I explained at Mobilezone and you will be able to call home very cheaply and be called for free. Keep in mind that Basel is 6 hours ahead of the Eastern US time zone.

It is a good idea to use the tram system to travel and if you want to see the city, just ride the trams as it is free with your stay at Hotel Rochat, they will give you a ticket to carry. Keep in mind that you should never have to show the ticket to anyone, they use the honor system however, from time to time an officer will ask everyone to show a ticket and you must have one. We always carry passports as well.

Down the street past the hospital, if you turn right, you will find a bank and I suggest exchanging US money for franks in the bank. I then suggest exchanging it back prior to leaving Basel the last time (not at the airport). Save out enough for the taxi fare.

More of Terry's comments

Clothing

While in the hospital, I wore gym shorts and a tee shirt for sleeping. Otherwise, street clothes are the norm. The room is not air-conditioned, but there is a vent for air ventilation. It was comfortable in May and July. Short-sleeved shirts are appropriate to allow access to your arms for blood testing. I have a chemo port in my right chest from treatments a few years ago, but it was not used in Basel. The nurses recommended I keep the hospital clothing separate from other clothing and wash them by themselves for one time. I used a plastic shopping bag to keep this clothing separate.

Communications

Don't forget to take a list of email addresses and telephone numbers. You may have an English speaking room mate, mine was Swiss, and we couldn't talk much!

The hospital plans to have Wi-Fi access, but as of July, 2009 it was not working yet.

Hospital Stay Schedule

1. Check in was 10:00 AM on Monday. Orientation, do's and don'ts, menu selection for the entire stay.
2. IV installed by doctor. Amino acids IV drip started at about 11:00AM at 200 ml/hr. Zofran tablet placed under the tongue for nausea control.
3. After one hour, went to floor 01 (basement) and received the isotope injection by the doctor. (My wife sat about 3 meters away from me.) No nausea, or vomiting. Didn't really feel anything. The injection is only a few cc's and happens quickly. (Blood counts won't drop for a week or more, and then will require about 6 more weeks to recover.)
4. By 12:30PM I was back in the shielded room with my roommate and eating lunch. There are six treatment rooms and seven beds allowing for 14 patients/week.
5. Lounged around about three more hours until the 1000 ml amino acid bottle was empty. IV then removed.
6. 3:15 PM, kidney baseline scan. Took only 5 minutes. (The injection has a little bit of 111-In to give off gamma rays so they can see where the Y90 went.)
7. Post treatment pancreas swelling usually not much of an issue. If there is a high liver tumor load, liver swells in its encasement and can/will cause pain from the treatment.
8. My wife was allowed in the hospital room, but she stayed behind the protection wall.

9. Second Day – Tuesday. 8:45AM 360 degree abdomen scan. 10:00AM full length body CT scan (no contrast fluid used) and 2nd kidney scan.
10. Met Dr. Mueller and Dr. Forrer at 3:45PM. They gave me the first impressions of the treatment.
11. Third Day – Wednesday. Breakfast at 7:30AM. Last kidney scan at 8:45AM (another 5 minute process). Met with Dr. Forrer at 9:45 AM. Discharged at 10:00AM.

Notes:

1. Need to stay away from contact with children under age 12 and pregnant women for a few days after leaving the hospital.
2. They will give you a letter to explain the treatment to airport security. I didn't get caught until Chicago. Then all the pocket-sized detectors on every Customs and Immigration official went off within 15 feet of me. They thought the letter was nice, but they used their own equipment to scan, identify the isotope, type of emission, and grade (medical, commercial, or military). It was very routine.
3. You may walk around the hospital grounds as long as you stay 3 meters away from other people and go back to your room to use the restroom. (They catch and contain **everything** – even shower and lavatory water -- and hold it in tanks for three months.)
4. They expect you to keep your room clean, and minimize throw-away stuff. They will clean and decontaminate the room after you leave in preparation for the next patient coming a few hours later.
5. I was told by the University of Iowa nurses to Dr. O'Dorisio to be really well hydrated before the PRRT. Do this to minimize nausea from the amino acids drip and the isotope injection. It worked for me. Do it.
6. Since I take an oral medication for hyperglycemia and my tumor exhibits some characteristics of a glucagonoma, I was told to take insulin and Sandostatin on the trip to control blood glucose levels after treatment. There was some possibility of a "glucagon release" from the PRRT. It didn't happen for me, but you might want to check with your physician.
7. I took all my normal drugs with me from home, plus those extra ones in item #6. I kept on taking them while in the hospital. I also took Imodium and Senekot along just in case the bowels caused some irregularities, as you understand. Nothing out of the ordinary happened.
8. Dr. Forrer requested blood counts and creatinine level every two weeks, to be faxed to Brigit Avis. No CT scan needed between now and next treatment scheduled in 9 weeks. (I have the CBC and metabolic panel done locally in Kansas City.)
- 9.

My Side Effects from the PRRT

1. No nausea or vomiting or pain (I have a low liver tumor load, 10-15% estimated.). Maybe, just a little bit of light-headedness for 10-15 minutes after the injection.
2. My fatigue was certainly noticeable, but not debilitating. We made short walks from the hotel to the Marketplatz to eat, etc. The tram passes were a big help.

Second Treatment Comments

Since we had done the tourist bit on the first trip, we shortened the stay for this last treatment. We arrived late Sunday night, checked into the hospital on Monday morning, released at 9:00 AM on Wednesday, and headed home on Friday. The process worked as smoothly as the first treatment. The doctor offered an appraisal of the results from the first treatment.

Good luck on your trip to Basel. Terry Yake.