Details of my illness

Werner Hunstein, July 2010

The first symptom of my AL-amyloidosis in 2001 was a decline in my immunoglobulin IgG level, which had remained a mystery for years. Otherwise, there was nothing unusual about my blood proteins, and the determination of free light chains was neither common nor possible back then.

Starting in the middle of 2003 some other symptoms appeared sporadically, including an occasional slight feeling of being unwell and infrequent signs of a bleeding tendency, e.g. ecchymosis on the lower arm, bleeding gums, and once periocular bleeding (so-called “pirate eye”). Proteinuria was determined after an extremely delayed examination of my urine by my general practitioner, and this was wrongly attributed to a mild case of type 2 diabetes. Then, echocardiography showed a thickening of my heart muscle with decreased movement of the posterior wall. The incorrect diagnosis was high blood pressure, although I swore to my doctor that I had NEVER had a high blood pressure reading before. She was convinced of this, though, and referred me to a cardiologist; however, I declined to have coronary angiography performed.

After seeing a nephrologist, who, despite my blood clotting problems wanted to do a kidney biopsy, I took my diagnostics into my own hands and visited a former co-worker, Prof. Haas at the Heinrich Heine University in Düsseldorf. He didn’t find anything that provided any further clues. As a final set of tests, I asked for a gastroscopy and a colonoscopy. To my relief, a polyp removed from my colon finally provided the diagnosis of AL-amyloidosis type lambda. And suddenly all the pieces of the puzzle fell into place.

After the diagnosis of AL-amyloidosis type lambda at the end of December, 2004, in Düsseldorf after a pacemaker implantation I began treatment according to a protocol of the Mayo Clinic at the beginning of 2005. However, it was unsuccessful. After our inquiry, the Mayo Clinic itself had traded its own method for a protocol of Palladini et al.: 0.22 mg Melphalan/kg body weight every 28 days plus 40 mg dexamethasone for four days. At the end of each cycle my symptoms returned, especially the tendency to bleed with ecchymosis after minimal pressure, and bleeding gums.

This therapy had strong side effects for me: suicidal depression; excitement followed by total exhaustion due to the high doses of dexamethasone; strong disturbances of my sense of taste.

At the beginning of December, 2005, after 14 (instead of 12) cycles, we contacted Angela Dispenzieri (Mayo Clinic) because she had already had experience with the Velcade therapy. Due to my fear of new side effects of Velcade therapy and the now more frequent dexamethasone therapy, however, I decided to avoid a new bout of chemotherapy. This was in spite of the fact that Dr. Dispenzieri had recommended taking only half the dose and additionally felt that "he should have some drug holidays." As a matter of fact, I still follow this piece of her advice up to today.

Shortly after terminating the Palladini therapy at the end of August, 2006, I got a call from one of my former coworkers and current physician Prof. Antonio Pezzutto of the Charité in Berlin. He mentioned a talk he heard by E.E. Wanker the previous day who reported having success with the tea polyphenol epigallocatechin gallate (EGCG) in inhibiting the formation of beta-amyloid fibers in vitro. Antonio Pezzutto recommended that I start an experiment on myself with green tea, which has a high content of EGCG, in order to try out the success in the laboratory on a patient. I was immediately persuaded and was able to begin right away as my wife had been drinking green tea for years: green Darjeeling of www.teekampagne.de.

I cannot recollect precisely the ensuing period of time; however, I "soon" started to feel much better. In parallel, there was the objective finding that my intraventricular cardiac septum (IVS) was reduced from 16.5 mm to a final thickness of 12 mm. My experienced echocardiologist, Derliz Mereles, and I had attributed its previous, unchanged size to a successful outcome of the Palladini therapy.

I regained my lust for life and could return to my active lifestyle, including taking a long walk for several hours without becoming breathless and travelling by train. I wanted to share this miraculous recovery with other patients and allow them to experience its benefits.

Unfortunately, from my colleagues I received only forced and almost pitying smiles because apparently the idea of "green tea" sounded so esoteric. At any rate, they did not want to simply accept the reason for my experiment as being the in vitro results of Wanker. Other

colleagues, like Dr. Dispenzieri, when asked about my amazing success that has continued until the present, expressed the suspicion that I may not actually have had amyloidosis in the first place. I had had this doubt myself from time to time, and so we had the diagnosis checked by a third party, Dr. Reinhold P. Linke, founder and long-time president of the German Society for Amyloidosis Diseases. His unequivocal diagnosis: AL-lambda amyloidosis. My physicians were also not prepared to report these findings in a publication, with the words, “But Dr. Hunstein, only one case and then green tea on top of it?”

Thus, I expressed my observations concerning my case in a letter to the editor-in-chief of Blood, with the question: “Epigallocatechin-3-gallate in AL-amyloidosis: a new therapeutic option?” (Blood, 2007). The magnitude of the reaction to the letter, which had been accepted after only four days, was astounding (see under Google: Hunstein and green tea; NZZ; RNZ; Stuttgarter Ztg; Badische Ztg.; Geo-Wissen; Spiegel online, etc.; inquiries from self-help groups in Israel, Australia, and the USA and from patients all over the world, even Darjeeling).

My colleagues in the field of hematology have unfortunately remained, with the exception of one, unimpressed to this day. Many patients who have been nevertheless taking EGCG in the form of green tea or green tea extract capsules as a self-treatment haven’t been consulted and might skew the results of a scientific study, according to the members of the local amyloidosis center.

With the improvement of my health, my scientific curiosity returned: how much EGCG am I ingesting and how much EGCG does tea contain on a per liter basis? What blood level of EGCG can I attain in comparison with previously reported studies of EGCG absorption in healthy volunteers?

Finding the answers to these seemingly simple questions proved to be very time consuming. After two attempts in East Asia, the tea campaign in Germany – in the form of the laboratory of Phytolab – found the solution: 10.0 g of tea leaves brewed in 1 liter of boiling water for 3-5 min yields 300-400 mg EGCG. With the help and understanding of Dr. Rupert Schreiner from Dr. Limbach’s laboratory in Heidelberg, I was finally able to determine my own plasma level of EGCG: 117-236 µg/L.

During the years of continuous well being 2006-2008 I had stable parameters with a stable kappa/lambda quotient.

With the excretion of more than 1 g/L in urine, however, the kidneys suffer irreversible damage, independent of any original kidney disease (Burton C, Harris KP; 1996). A dramatic, exponential increase in uremic blood values is the ensuing result. This was also my situation by the end of December, 2008. The nephrologists, well familiar with peritoneal dialysis, started this treatment with me immediately, and it continues until today.

I was not spared the age-associated disorder of an enlarged prostate and was operated in July. By September, I again had pronounced pain and difficulty in urinating, and another operation at the end of October was unavoidable. In its aftermath, I developed a diffuse peritonitis that became life threatening. By this time, I had already limited my tea-based intake of EGCG due to the problems with urination and had begun to take capsules containing green tea extract (GTE).

At the end of the successful treatment for peritonitis by Prof. Zeier and Schwenger from the local Kidney Center, I noticed (as I described in my article on the website) the not unexpected return of symptoms of amyloidosis: an increase in the IVS by 2 mm, a deterioration of cardiac function, a decline in blood clotting factors IX and X with an increased bleeding tendency, and a thickening of the tongue.

Now the results of the pioneering experiments of Klaus Altland on himself (see in the reference list Altland, K., R. Schreiner, and W. Hunstein: Of Green Tea, Black Pepper, and Amyloidosis) started to bear fruit, for me as well as for other patients who were taking EGCG under their own direction. By taking 900 mg GTE plus 20 mg piperine plus 200 mg vitamin C three times daily, I was again able to achieve values between 120 and 190 µg/L EGCG, with a maximal value of 604 µg/L. Klaus Altland had also discovered the positive effects of an empty stomach on the absorption of EGCG, and he therefore recommended not eating two hours before and two hours after taking the dose.

With the immediate increase in intake thanks to the information from Klaus Altland's study on himself (and checking EGCG levels in plasma and peritoneal lavage fluid by R. Schreiner), it was possible to reverse the relapse without chemotherapy.

This had been an undesirable and threatening incident but also an exceptional learning experience!

For the past several months, my urine production has declined and the usual increase in uremia parameters, weakness, tiredness, and dizziness has followed. According to my nephrologist Prof. Vedat Schwenger, this is due to the combination of renal anemia, decreased blood volume, a previous posterior wall infarct, and, even though improved, amyloidosis symptoms of the heart.

In fact, with the help of these new findings, I was successful in treating the reappearance of my amyloidosis.

My hope, that my colleagues would finally have no objections on its use, after this apparently esoteric magic agent has found a scientific explanation, remains unfortunately blurred. Because they remain closed- without giving a reason for it. A so called active ignoring, just looking away. Also the NCT, the "translational", which goal and own defined task is the implementation of new scientific findings into practical experience remains, despite detailed explanation so far, unfortunately closed.

I’ve managed at present for four years without chemotherapy and at the same time kept my disease under control with this symptom-oriented therapy. When and who is finally going to start an extensive study?