

Statement of W. Kenneth Bays

I am a retired dentist, 72 years old, who practiced from 1952 until 1995. In August of 1995 I was diagnosed with a massive cancer of the liver. At the time, I was semi-retired and living in North Georgia. Having practiced dentistry for over 43 years, I was very aware of educating patients and offering different treatment options. It had always been my belief and practice that patients themselves have the right to final determination of their treatments. I was about to find the concept of patient education and patient determination would not exist in the world I was about to enter.

Other than a loss of my kidneys, the treatment for cancer was successful. I was, however, not prepared for what was coming next. It was much later before I understood the treatment options and choices available to me. I was of course entering into a very different world of the dialysis patient. In this world of dialysis, even though I am a dentist, and understand medical terms, I was appalled to find that dialysis patients have no rights of self-determination. Never before had I been in the position where treatment options were not even offered, much less explained.

Vascular access is the **key** to proper dialysis. Without the proper working access you cannot dialyze a patient. I was referred to a vascular surgeon. There was no preceding exam or discussion of treatment. I was just set up for surgery. A vortex graft was put in instead of a A-V fistule. The graft is a treatment of last choice. I was now becoming fully involved in the wonderful world of numbers and dollars. I was just another money cow with a market value of \$100,000.

I next went to the nephrologist in North Georgia who turned me over to his physician's assistant. I tried to get some information but was cut off with the remark "patients who have never been sick have a hard time accepting." I was taken on a walk through the clinic and my treatment was set up on a time slot basis so as to maximize the number of patients per day. I was dialyzed twice a week. As a result of the inadequate treatment, my back itched as if there were a thousand mosquitoes biting it. This was due to a build up of phosphorus. This caused me to rub my back raw on the door facing. I had to force myself to eat, as well as watch my diet and fluid intake carefully. I was also taking 8 times the normal dosage of blood pressure medications because of the build up of toxins.

I was sick all the time. Dialysis was "**HELL**." The cramping, changes in blood pressure, and the pain of being "roto-rooted" with needles the size of a ten penny nail by untrained personnel with no medical background made me a "nervous wreck." The cramping and changes in blood pressure were a result of removing the fluid from the blood too fast. I was at this facility for seven months. I do not wish to name the facility in particular as this is a systematic problem with the industry.

I had to go to South Georgia on business, so I set up an appointment at the Mitchell County dialysis clinic. The facility is a branch of the Archbold Hospital in Thomasville, Georgia. Archbold is a non-profit public hospital.

As of that day, I moved into a different world of medicine, and the caregivers were nurses trained in dialysis. My new doctor, Dr. Merrill Hicks, the nephrologist on rounds that day, stopped to talk. He explained to me home dialysis existed. He further explained to me if I would do my part, I would have to take very few medications and would not have any diet restrictions. I now do dialysis 6 nights (8 hours at a time) a week.

I have now been doing home dialysis for three years. The total cost of my care is substantially less than the average dialysis patient. I have become a productive member of society again. I expect to live a normal life within the confines of my impairment. I am one of the very fortunate few that had the means

to get adequate treatment.

Approximately 2 years ago, I became involved with the Network "6." I was first on the consumer committee and then next on the board of directors. The Board consisted of 18 industry members and 2 patients. I found out very quickly that the Network was constructed to work for the betterment of the industry. One of the primary problems the Network was concerned with was non-compliance of patients, and how to handle them. There is one particular that I remember quite well. A patient wanted to continue working. This interfered with the clinical scheduling so he was judged non-complying.

The statistics that are collected by the Network are, in my opinion, a joke. If you want to get true data, you should get it from the backs of the machines and comply it by a central computer. Wal-Mart keeps track of tens of thousands of items from thousands of stores. It would be child's play to create a database of dialysis patients from the data collected by the machines. It is my belief this would upset the gravy train if this was done.

I never reuse a dialyzer. Reuse according to the literature, degrades the efficiency of the dialyzer to remove the larger more toxic particles and the chemicals effect the proteins in the dialyzer to produce toxins.