

My Fight Against Cancer

This story is not easy to write, but I hope to help someone who is about to make the same mistake I did when I was 15 years old. If they have already made the mistake, maybe this will help them correct that error. I am now 45 years old. I began smoking when I was 15 and by the time I was 17 I was smoking at least 1 pack per day. My father was a doctor and he kept telling me that smoking was bad and caused cancer and other problems related to the heart and lungs. But, like most kids, I knew more than my parents did. I knew lots of people who smoked and they didn't get cancer. I also knew those who never smoked and they did get cancer. Besides, smoking was cool back then.

Over the years, I have tried to quit smoking several times, but I never managed to do it. You would think it would be easy, but it wasn't for me. My brother quit "cold turkey" and it was easy for him. So why couldn't I quit the same way? It might have been because he never smoked as much as I did, never smoked for as long as I did, or maybe he just had more willpower and wanted to quit more than I did. Still, that's no excuse not to try to quit. The "Patch" was made available by prescription only. I asked my dad for information about it even though I wasn't sure I was ready to quit just yet. In about a week, I received the information and a full supply of patches. My father had purchased the prescription for the entire program for me since he knew I couldn't afford it. Of course, now the "patch" is sold over the counter, you know the one with the "steps". I decided to give it a try and it worked! You still have to want to quit and you can't have a cigarette while you are using the patches, or you could die. It certainly made everything easier for me. It also made it a little easier on my husband . . . I wasn't quite so cranky and didn't get mad at the least little thing.

When I was 40 years old, I began joking with my husband and friends that my body was beginning to fall apart. My teeth had gotten to be so bad that I had to have them all removed and begin to use dentures. It wasn't too bad, except that I had to be given several needles to get me through the procedure and I have a terrible fear of needles. Thanks to the caring dentist and his assistants I was able to get through the ordeal. I would return to the dentist every 6 months for a checkup to be sure my dentures were fitting properly and not causing any problems in my mouth. On one such occasion, the dentist found a spot on my tongue that he was concerned about. He sent me to an oral surgeon for his advice. The oral surgeon suggested a treatment and I was to return in 2 weeks. At that time, it was decided that I should have a biopsy to determine what the problem was. I was sent to another surgeon for the biopsy. They cut a piece of my tongue off and sent it to a lab for analysis. A week later I return to the oral surgeon to find out what the biopsy showed. He said, "There's no easy way to say this, but you have cancer." I told him that since my father was a doctor and I was going to talk to him, I wanted to know just what kind of cancer I had. He told me it was squamous cell carcinoma. I was so scared, cancer, "the big C", what could be worse? As I walked in the door of our home, I was crying and my husband asked what was wrong. My reply

was "Why did I even bother to quit smoking?" My husband was in a state of denial and wanted a second opinion. It just couldn't be cancer. I called my father right away. When he said, "That's a tough one", I knew I was in real trouble. He always was one to tell you what you needed to know in the case of a serious problem. He also knew that I was informed enough to know that cancer was not something to ignore or put off treating.

The following day I had an appointment with an ENT (ear, nose, and throat) doctor who specialized in cancer and other problems corrected with surgery. He asked me if I smoked or drank. I was never a heavy drinker but I was considered a heavy smoker even though I had quit 3 years earlier. After examination of my tongue and the biopsy results, he was all for immediate surgery. I felt so overwhelmed that I had to tell him no way could I have surgery in just 3 days. That wasn't enough time for me to gather the information I needed to make an educated decision about the method of treatment. I had 2 choices: surgery or a combination of chemotherapy and radiation. I knew I needed my father's input before I could say one way or the other. I was also very much afraid of surgery since I knew it would mean needles. I learned that radiation could be used on the head and neck areas only once in your lifetime. Because of this, most doctors believed that radiation should really be left for those areas that you cannot surgically take care of. In my case, surgery was the best choice to make. When we asked if smoking caused this cancer, the surgeon couldn't say yes but he couldn't say it hadn't either. However, most cancers in the mouth are caused by smoking, so the logical answer was yes. I ended up scheduling the surgery for the day after Labor Day so that my parents, mother-in-law, and husband could be there with me.

The hospital said I had to pay one half of the expected bill before I could be admitted. I didn't have the money so did that mean I couldn't have the surgery and would die eventually of cancer? Fortunately my parents paid the necessary amount, but I assume the hospital would not have turned me away. Before the surgery, the doctor reminded me that I would be in the hospital for at least 5 days if he only had to remove a small portion of my tongue. If the surgery was extensive, I would need a skin graft and I would need to stay about 10 days. If a skin graft was needed, it was likely that I would have a tracheotomy as well. This would be necessary since the tongue could swell and completely block my breathing. A tube would be placed into my throat through the skin at my neck to enable me to breathe. This would be removed later and would leave a scar. However, the surgeon wouldn't know if this would be necessary until he was in surgery. So, I went into surgery without knowing what to expect when I woke up. Happily for me, there was no tracheotomy. My tongue sure felt different, numb and twice the normal size. I thought I would have a hard time talking, but I was able to talk pretty normal right away. I was released in 3 days since I was doing so well. As far as they could tell, the cancer was gone!

I would have to see the ENT doctor every month for awhile and then every 3 months for the next 5 years to be sure the cancer didn't come back. I could handle that as long as I knew the cancer was gone. There were some minor problems in the first couple of months but after that I was just fine. By the middle of April the following year, I began to have pain on the left side of my face. I saw 2 or 3 doctors who were all convinced

that I had TMJ (temporomandibular joint syndrome). The pain was worse when I ate. After awhile, the pain was so bad that even extra strength aspirin wasn't working. My father gave me Valium to see if that would relax me enough so that the aspirin would relieve my pain. That worked for a short period of time. After that, we tried morphine pills. This was a strong narcotic and did help ease the pain somewhat. I continued to see the doctors and they continued with the TMJ diagnosis. Finally, my father referred me to a neurologist. The neurologist tended to agree with the diagnosis of the other doctors. When I asked about having a MRI (magnetic resonance imaging), he stated that it was too expensive (over \$1,000) and it wouldn't show anything anyway. The pain continued and the doctors maintained that TMJ was still the culprit. TMJ is usually caused by the joints being out of line so we even tried a specialist who began to manipulate my jaw and temple in order to relieve the pain and perhaps move the joints back into place. However, the manipulation didn't work either. The pain continued and was getting worse daily. I saw the neurologist again. When asked about a MRI, he again stated that it was too expensive and wouldn't show anything anyway. By Thanksgiving, the pain was so bad I couldn't even enjoy turkey dinner (one of my favorite meals). By December, I had lost a lot of weight, was in constant, overwhelming pain, and now it hurt to swallow so my husband took me back to our family physician and said, "Do something!" I was admitted to the hospital where I would finally get some tests to find out what the problem was.

We had to find out why I was having such difficulty with swallowing. They did an endoscopy. This is where they insert a miniature camera down your throat and into your stomach so they can see a picture of what is happening. They found a duodenal ulcer that was most likely caused by the large amount of pain relievers I had been taking. They also did a swallow study. They give you this chalky stuff to drink and watch by way of x-ray to see how it goes down the throat and through the swallowing action. They found that the mechanism for swallowing just wasn't working right. Since I couldn't swallow, they did a flexible laryngoscopy and inserted a feeding tube into my stomach. This tube is about 9 inches long and comes out of my stomach right at my waist. I had a spinal tap done. I was given IV fluids. Drugs could be given via IV tube or the feeding tube. All my food was liquid. I had a blood test taken. They decided that since I was going to have many more blood tests and my IV would need to be changed every 3 or 4 days, they would give me a Groshong Catheter. Give my intense fear of needles, this was the best thing for me. This is a tube that is inserted into a vein near the heart and comes out in the middle of your chest. This meant that there were 2 tubes hanging off my chest, 1 for blood tests and 1 for medication. The only bad thing about the catheter was that you couldn't get it wet so bathing was not an easy task. I also had a CT scan and finally had the MRI. Both of these are specialized kinds of x-rays and were painless. The problem with each is that you have to be perfectly still for several minutes. That's pretty hard for anybody to do, but for me it was almost impossible since I could choke on my own saliva. However, I did get through both tests and the radiologist (person doing the test) complimented me on how still I had been considering my difficulties.

By this time, there was extreme pain on the left side of my face from my temple down my jaw. My mouth on the left side was drooping. My left eyelid didn't blink or close on it's own. I couldn't swallow at all. The pain was so bad that they placed me on a special

pump. This pump would continuously give me a measured dose of a potent pain reliever. I was also given a small hand pump by which I could give myself another measured dose of the narcotic if the pain was extremely bad. But after awhile, even that didn't work.

My days revolved around various diagnostic tests and blood tests. I was too tired to do much but lay around in bed and let them do whatever they wanted to do to me. Toward the end I was able to walk up and down the hall with my IV pole and the machine and the tubes that went with it. After Christmas, the test results were finally in. I had decided that when that happened it would be a great relief and we could treat whatever the problem was and it would be over. Wrong! I was told that I had cancer located at the base of my skull and it had spread along both sides of my head but primarily affecting the left side of my face. This cancer was not operable because there was too large an area that was affected. Some Christmas present! It was a good thing that back when I had cancer of my tongue that we decided to operate rather than to do radiation therapy. This cancer would need radiation and chemotherapy treatments. I spent Christmas and New Year's in this hospital. The day after New Year's Day I was transferred to another hospital for the radiation and chemotherapy treatment.

This hospital 45 minutes away from home. I was placed on the cancer ward and had a new doctor, an oncologist (a cancer specialist). I had a CT guided biopsy (a CT scan helps the doctors locate the exact location where the needle is to be inserted) done on my cheek to establish the type of cancer so that the correct treatment could be given. My husband was told that we should think of my life in terms of months, not years. My husband informed my parents of this terrible diagnosis. They decided that they would not come to see me because they knew that if they showed up, I would believe that it was an extremely bad situation and that I was probably going to die. This way I would have some hope and my parents would keep in touch by phone with my husband and me. Before anyone thinks this was a bad thing, let me say that I feel they did the right thing. I knew this was a serious situation, but didn't feel that I was going to die yet. During my stay in this hospital, I lost my speech and would have to write everything I wanted to say. I spent my 12th Anniversary here (pretty romantic). My husband was always there with me as much as he possibly could even though it wasn't easy on him, physically or emotionally. He was working days and playing in a band in the evenings. These jobs were not always in the same city as the hospital so he would do the job and then come see me and stay overnight in a hotel not far from the hospital. He would have to go home every 2 or 3 days to get clean clothes and check mail, etc.

After getting all the medical history from me and going over all of the tests my family doctor had requested, it was decided that I needed a chemotherapy consisting of specific chemicals and the maximum amount of radiation that was felt to be medically acceptable. The chemotherapy was going to be quite aggressive and they would inject extremely bad chemicals into my body through the Groshong catheter to kill the cancer cells. The only problem with that is that the chemicals also kill some good cells too. Most often people get very sick and lose their hair. I didn't like the idea of losing my hair, but I knew it would grow back. The radiation can also make you sick, extremely tired and weak, and cause you to lose your hair if the chemotherapy doesn't. What choice did I have? I had

to make the best of a bad situation. I got into a routine very quickly. They woke me up every morning for radiation therapy at 7 a.m. I was being fed liquids by tube 24 hrs a day. I had to ask for help to go to the bathroom. They made me walk down the hall and back to my room at least once a day. The dressing around my feeding tube had to be changed 4 times a day. Unfortunately for me, I became very sick with the first chemotherapy treatment. We began radiation after that. I was given another chemotherapy treatment and became very sick again. It was definitely not romantic, but I celebrated my wedding anniversary here. After the second chemotherapy treatment they decided that it was enough and I could be released to a nursing home facility only a block away from the hospital so that I could continue the radiation treatments and not have to spend 2 hours on the road every day.

I was only 43 years old so being in the nursing home was not easy to get used to. However, the one I went to looked a lot like home with pictures on the walls, nice carpeting, two beautiful visiting areas, and yet it had the necessities of a nursing home including a rehabilitation area. The facility allowed pets to be brought in to visit all of the residents and my roommate was allowed to keep two birds in the room (in cages). Sometimes they were pretty noisy but this was my roommate's home now and she couldn't give away her good friends. She used to let them out of their cages each day to fly around. She said they might land on my head, but they never did. I didn't mind them at all even though they were a little noisy sometimes. On the day I arrived, I met my roommate and immediately she told me she was going to take me to the main activity room to play Bingo as soon as I got a bit of paperwork taken care of. There was always something planned each day, but I didn't have to partake of any of it if I didn't want to. There were also religious services available although the only choices were Lutheran or Catholic but you were welcome to attend whenever you wanted. There was a TV in our room so that wasn't too bad. Since I wasn't able to swallow I was not required to go to the dining room. I was allowed to sleep as late as I wanted since I wasn't sleeping well at night and always had to wake up for medicines and when the food ran out and I needed more. That buzzer was always going off just as I was falling asleep. I had to be up and ready to go to radiation therapy by 9:30 a.m. but that was better than 7 a.m. I was encouraged to do things instead of staying in bed all day. If you stay in bed all day, you can't regain any strength and no amount of physical therapy will help. I was so weak that I could barely walk from my bed to the bathroom which was only about 10 steps away, therefore, I was using a wheelchair to get around for awhile. I still couldn't swallow so I was hooked up to a machine that pumped liquid food into my stomach all day and all night. Wearing clothes was difficult since I had to worry about the tube hanging out of my stomach and its placement was very inconvenient. Even after I didn't have to use the wheelchair any longer I had to have help going to the bathroom for awhile since I had to bring the IV pole with machine and several feet of tubing with me. After a period of time, I was able to get around with all this equipment by myself. Eventually, I was allowed to unhook myself from the machine and walk outside if the weather was good. Eventually I was able to walk around the building at least once. I got so good at cleaning the site around the feeding tube that the nurses let me do that while they got my medicines ready for me to put directly into the tube with a large syringe. I still had to write everything I wanted to say. If the nurse turned her back to me and I wanted her

attention I had to clap my hands. It felt like I was calling a dog but they understood it was the only way to get their attention. In order to talk to my parents when we called them we had to come up with a system of communication. They could tell me anything they wanted but they could only ask yes or no questions. I would tap on the phone once for yes and twice for no. I would also be started on a routine for speech rehabilitation and also a rehabilitation program designed to get me walking again and regain some of my strength. My husband started a dangerous habit. He began to come into my room and tell me that something had jumped into his pocket and would I help him get it out. There was always a stuffed animal of some kind. Some were the real Beanie Babies and then there were those that were similar to the real thing. I now have 100 of these little animals and call them my menagerie.

At one point, the site of my feeding tube became infected. Chemotherapy affects your body's ability to fight infection. This infection was so bad that I had to be taken to the hospital and placed in the ICU unit. My husband was told that they didn't expect to see me in the morning. It was up to my husband to give this horrifying bit of news to my parents and his mother. Well I was still there in the morning and spent 2 more days in the ICU. While there, I thought I saw my cat, Mitzi, in the room! I don't remember anything about my days in the ICU, but my husband says I was given quite a bit of blood and other drugs. They kept me in the hospital for another 2 days and then let me return to the nursing home. Since I was to be given more antibiotics which could be hazardous to my roommate, I was given a room all to myself. At least this time I was by a big window and could see the outside world. I could watch the snow falling on the parking lot just outside my window. I always did like snow unless I had to drive in it or it was really cold out too.

Finally, my radiation therapy was over. I went Monday through Friday until I had a total of 30 treatments. There were a few days I couldn't go because I was too sick and a couple of days where the equipment was being updated and getting routine maintenance. The oncology radiologist was very impressed with my progress. You had to be extremely still during each treatment. Normally they use a wire mask to use as a roadmap to know where to point the radiation beam. But with my swallowing problem, that was going to be very hard to do. I was constantly throwing up after getting medication and if I moved around too much. I always carried what I called my "bucket" no matter where I went. I also felt I would be claustrophobic if I used the mask. So they used black marks, like magic marker, to show where they had been and where they were to go next. These marks had to remain on my neck and face the entire time I was undergoing radiation treatments. The radiation itself was not painful, but I sure looked funny with all those markings on my face and neck. Each day I would come into the radiation department and everyone wanted to know what animal I had brought with me. The animals were my special friends that I took everywhere and they helped me keep my mind occupied during treatment. When they actually gave me the radiation, I had to be very still and the radiologists had to leave the room. They watched me from a camera just outside the room. If I felt I was beginning to choke or needed to throw up, I would pick my animal up off my stomach and wave it to signal them that I needed to sit up. I only had to do that a couple of times. After about 6 weeks the radiation therapy was over

and I was allowed to begin washing away the marks. It took a couple of weeks before they were gone.

During my stay in the nursing home, I continued to visit my oncologist. He would take blood tests and check to be sure the cancer had not come back or moved somewhere else. He was impressed with how well I was doing and that my spirits were always pretty good. At one point, I had the nursing staff at the home call and ask if I could have a weekend visit home. Three things had to happen before they would let me go home. First, I had to be able to walk up and down steps particularly since we lived in a mobile home. I had been working on this in physical therapy and I was pretty sure this was not a problem. Second, I had to be able to talk. Through speech therapy I was able to talk again. I sounded pretty funny, I couldn't talk as loud as usual, and it was a little difficult to understand what I was saying, but I could talk. Finally, someone always had to be with me. My husband would be there all weekend and I knew he would not leave me alone. The doctor said it was okay so the nurses put together the medicines I would need to take and gave me a schedule to follow with regard to taking medicines and cleaning my catheter and feeding tube. That Friday I went home and the visit went very well. The only problem was my cat. She hissed at me and wouldn't even come near me. Since I had been gone for several months, it was like she had never known me. She never did like kids and it always took a long time before she would come out in the front room if we had guests. I returned to the nursing home on Monday. On Tuesday, I had an office visit with the doctor. He inquired about my home visit and I told him I was ready to go home for good. He said okay and I went home that day. I had spent Valentine's Day and St. Patrick's Day in the nursing home was very happy to be going home at last.

It took the cat awhile to get used to me again, but things are back to normal with us. I still cannot swallow and still have to use the machine to eat. I have gained back most of the weight I lost and do well to keep it where the doctors want me to be. In case I get sick again, he feels that I should keep my weight at around 125-130 pounds. I still don't have much strength. My face still droops on the left side and has no real feeling. When I touch it, it just tingles. I cannot feel myself drool on the left side or feel my nose run on that side either. My husband has to tell me and we have developed a movement he makes to let me know without saying anything so he doesn't embarrass me, or anyone else in the room. The pain is finally gone. I still talk funny. I have trouble hearing in my left ear. My left eyelid does not blink, but with the help of a gold weight that was inserted in the eyelid and a little concentration, I can close my eye without using my finger. These things were caused by the damage done to 2 or 3 nerves on the left side of my face. I believe the radiation has affected my memory a little since I have more trouble remembering things than I did before the treatment. My face and neck are still a little red, like sunburn, and the skin is very dry on the left side. Sometimes I can take my fingernail and actually scrape off bits of skin. After being in the sun for only 5 minutes, I look like I have a nasty sunburn. Once I go inside, it goes away. I have changed the feeding tube to a "button". This is located in the same place, at my waistline, but at least the button is even with the skin instead of being a tube hanging out about 9 inches. My Groshong catheter had to be removed due to infection. Clearing my throat and mouth of saliva is still an embarrassing procedure.

Every day I get up and get dressed around 9 a.m. However, I have been tossing and turning in bed since 7 a.m. After I get dressed, I must eat. I am still eating by tube and usually don't have to use the pump any more. If I have to use the pump the least amount of time it takes to eat 1-8oz can of food is 1 hour. Most often I can just let it flow through the tube by gravity. My 1st meal of the day usually takes about ½ hour from beginning to end. I prepared the medicines the night before because there are 2 pills that need to dissolve. I take the meds 1st and then "eat" 2-8 oz cans of food. My "button" does leak some so I must not do much of anything for about 1 hour after eating. At about 10:30 a.m. I can do what I want but my energy level isn't very high. Normally, I sit and watch TV and do some cross stitch or knitting. Sometimes I read or play games on our computer. There are 2 pills to dissolve so I put them in a little water at noon. I prepare the meds and eat lunch at 1 p.m. Meds come 1st and then the 8 oz can of food. Again, I must not do too much for about 1 hour. By 2 p.m., I can do what I want, but my energy level dictates what and how much I can do. At 4 p.m., I prepare the pills again since dinnertime is at 5 p.m. I also must change the dressing around my "button" at this time. Normally, I can get by changing the dressing now and before bedtime, but sometimes I must change it more often. The "button" does allow some leakage around the plastic tube where it enters my body. The more physical I am, the more it leaks. This makes even simple housework chores difficult to do without leakage. I have had to change the dressing after only 1 hour in some cases. Dinner consists of meds 1st and 1-8 oz can of food. By 6 p.m., I can do what I want again. At 8 p.m., I prepare my meds again so that the pills have time to dissolve and I can eat at 9 p.m. At this time, I also prepare my morning meds and place them in a small covered container. This way I don't have to wait for the pills to dissolve in the morning. By 10 p.m., I am ready to take my bath and go to bed. After bathing, I replace the dressing. Usually, I try to read for at least an hour, but never past midnight.

Some days my energy level isn't really any higher, but I'm so bored that I try to do some house cleaning. I live in a mobile home so it never took long to clean before. But now it takes 2-3 days to clean a room well. The hallway is all I can do in one day since there are 5 bookshelves to dust and pictures on the walls to dust and clean the glass. I have to have someone come in every 2 weeks to clean the bathrooms, wash the kitchen and hallway floors, and help me remake our bed. While I watch TV, I usually try to do some cross-stitch, knitting, or crochet. I have made bookmarks for the hymnals and Bibles at church. I can do the laundry, but since everything is no iron these days, it really isn't too difficult to do unless I'm really not feeling well. I can still drive so every now and then I drive to the grocery store to Wal Mart. Both of these stores are within 2 miles of my home. I can only do this if I don't have to buy much or spend much time in the store. When the weather is real nice I walk up the street to our mailbox. I'm pretty winded by the time I get back but it is a nice feeling to be outdoors in the sun. If it is windy, I make sure to wear my wraparound sunglasses to protect my left eye. The slightest bit of air moving hurts my eye since I can't blink and keep it from drying out. On Sunday, we go to church in the morning so my eating schedule must change and I do every meal about 1 hour earlier than normal. I have joined the church circle groups, but that doesn't change my eating times. The group of cancer survivors I visit with means that my eating is a little

behind schedule. I am also part of another group who is trying to get the word out to kids about the dangers of smoking. I am more than willing to adjust my schedule around for this group. Perhaps I will even meet with students and let them watch me eat so they can see part of what I live with and speak to them about how my life has changed. I don't cook for my husband too often. It's kind of hard to be around food that you know you can't eat. It's also hard to season food since I can't test it. My imagination takes over whenever I smell food so that I can taste it. I'm getting used to not eating since it has been over 2 years since I've had anything but liquids. Everybody knows it's pretty special for me to cook.

My husband isn't very comfortable about leaving me at home alone when he has to work. There is a special telephone system that is connected to the hospital called Lifeline. It also has a necklace to wear. It's that "Help, I've fallen and I can't get up" thing. If I push the help button the hospital can call me and if necessary there are 3 friends that can be called to help me. If they can tell there is a problem, they can send an ambulance for me. I must remember to push the reset button once every 24 hours. If I go somewhere, there is a button I pull up which lets them know I'm not home. If even says "Away". When I come back and push the button down it says "Welcome Home" and the hospital knows I'm home again. When he does have to be gone, my husband always calls at least twice and sometimes more just to be sure I'm okay.

I still have to visit 2 doctors on a regular basis. Both want to see me every 3 months. We alternate appointments so that I see a doctor every 1 ½ months. The surgeon and the oncologist keep a lookout for any signs of cancer. I must also visit my family physician at least once a year for female examinations. Of course, I must also examine my body for any signs of lumps. I do this at least once a week. Obviously, if I find something, I must see the oncologist as soon as possible. On one Friday night, I discovered a lump on my side quite by accident. I just happened to be looking in the mirror and standing in just the right place to see it. Of course, there are no doctors in the offices on the weekend. So I called my father in Florida and described the lump to him over the phone. He said it sounded like a lipoma. This is a fatty tissue tumor and they are never malignant. He told me not to worry, but with my history it would be best to check it out. On Monday, I had an appointment already with my ENT doctor. While I was there, I talked with him about it and even showed it to him. He said it appeared to be a lipoma. I still wasn't convinced, so I immediately went to the oncologist's office. When they asked if I had an appointment, I started to cry and said no but I had found a lump. They worked me into the schedule. Fortunately for me it was really only a lipoma. Unless it changed in some way, the doctor said I didn't need to worry about it. What a relief!

Unfortunately, once I go to bed it doesn't necessarily mean my day is over. I have difficulty falling asleep. Even without a cold I have a problem, but with a cold it's even worse. I am no able to breathe well with my left nostril and due to the choking problem I must not lay on my back. I use a special wedge shaped pillow so that I can sleep. After I have fallen asleep, I always wake up at least twice having to clear my throat. Normally, I can go back to sleep, but not always. By 7 a.m., I am awake again to clear my throat and

this time I usually can't go back to sleep but I always try. Then at 9 a.m. my day begins again.

The cancer still rules my life. We know that the cancer will come back. We just don't know where or when. Therefore, it will always rule my life. I try not to let it get me down. There are more than just the health problems to overcome. Traveling anywhere is not easy because I must plan my travels around my schedule for eating and taking medicines. Doing this while driving is impossible. Even if someone else is driving, it isn't easy. I have to take enough medicine and food for the entire day in case something happens and I don't get home at the time I thought I would. What if the car breaks down? Winter is worse. What if the weather is so bad I can't go home? I can't just go to a McDonald's and eat any more. When I go to my parents, I have to send at least 2 cases of food by United Parcel so I have enough food while I'm there (depending on the length of my stay and how many cans I need to eat per day). I have to use a special cushion to sit on since I sit so much of the time due to the loss of strength. I also have a special pillow to prop me up when I sleep so I don't choke on my saliva.

There were several emotional battles to be fought. The first battle was my fear of needles. This is still a big problem for me. Needles put me in a panic! My doctors were aware of this and gave me the Groshong Catheter. That was extremely important to my emotional distress during the testing procedures. This has had to be removed since that time due to an infection that was similar to having the flu. If the catheter had not been removed, I could die from the infection so I had no choice in the matter of its removal. Of course, the fear of the unknown is a problem to almost everyone. What test was going to be done now? How is the test performed? What would the test show? What happens next? What can be done about the pain? Most doctors will sugarcoat things until they know for sure what they are dealing with and what can be done about it. My initial physician was a family practitioner and was only able to tell me about cancer treatments in very general terms. The oncologist was the one to answer these questions. But since everyone reacts differently to the treatments, he couldn't tell me for sure what to expect. We couldn't even be sure the cancer would be completely eradicated. Chemotherapy was particularly scary because the chemicals to be used were dangerous and even kill normal cells as well as the cancerous ones. The big battle now is when will the cancer come back? Where will it be in my body? Will it be treatable? Will I die from it? These are big questions, but I will only be able to deal with them when it happens. I try not to let it affect my daily life. Sometimes that is pretty difficult.

Of course, when I was admitted to the hospital, the staff brought something to my attention that I had never really thought about. It was called an "Advance Directive". I had to decide who should make decisions about my health care if I became unable to do it myself. I also had to decide how far we should go to keep me alive. What if my husband didn't understand what the doctors were telling him? My parents could help but they were far away in Florida. What if my husband couldn't be reached at that moment? He played drums in a band and most clubs would not interrupt a song. Most would just wait till the band took a break before telling him and what if they forgot. My husband always made sure the hospital and nursing home knew where he could be reached. The band

was aware of my problems and would not object if the song were interrupted for an emergency. Did I want to be kept alive on a respirator? Did I want to continue tube feeding if it's all that was keeping me alive? If I stopped breathing, did I want to be resuscitated? Did I want to be hooked up to a kidney dialysis machine? Did I want to donate my organs and would they even want them since I had cancer? These decisions were very difficult for me to think about. What would my husband do? I didn't worry too much about the financial question because we didn't have much money or property anyway. I trusted my husband to do what was right. But what if I didn't trust my husband with my finances or to make health decisions for me? We have talked about all these things, but we won't know how we will react until it actually comes up. At least he will have some idea of what to do. We talked about what he would want even though we feel that he will have to make these decisions on my behalf long before anyone would have to make these decisions on his behalf. What if I have to go back to a nursing home? My husband is aware that I liked the one I was in and if I must return to one I would prefer this one. He knows what to look for in a nursing home if I must go to a different one. I don't want him to feel bad about taking me to a nursing home because I know he can't take care of me properly. It also gives him a place to be "normal" if I'm not at home. He can be as emotional as he wants where he is comfortable and he doesn't have to worry about me seeing him fall apart. The other obvious question we had to face is what happens if I die? Where will I be buried? Will I be cremated? Do I want a church service or just a memorial? I have answered these questions, but it was very hard to even think about that outcome. Do I need a Will? I don't have any money or property like a house or car. Even if I did, it would go to my husband automatically. However, there are some things I wish to have given to other people. My husband is aware of many of these things now.

How do I get through each day? I used to think it would be nice to not have to work and stay in bed all day if I wanted, but it has gotten very boring. Now that I look back on it, I enjoyed being a secretary and I will never be able to do that again. Aside from the physical difficulties that would affect my work, not too many people would hire me knowing that I had cancer and especially if the cancer could come back. It has been found that your health is better if you maintain a good outlook on life. In other words, the more you laugh, the better you feel. It has been found that depression leaves your emotions in an "I don't care" attitude and this kind of attitude can affect your health as well as your mind. When we originally found the cancer on the tongue, I was told I might have to have a skin graft. There isn't anything funny about a skin graft but I was able to imagine a situation regarding the area the skin would be taken from and found something to laugh about. My left eye not closing gave us the chance to have a nightly routine. My husband would tell me to close my eye and I would use my finger to close it. Now I don't have that problem since I had a gold weight placed in the eyelid to help it close. My disability does allow me to park closer when I go to the store which is good if you go to a large mall. I have a sign that I place on the rearview mirror giving me this privilege. Not exactly funny, but it is something good that came out of the cancer. My disability leaves the door-to-door salesperson very uncomfortable so it means a very short time that I have to listen to them. My standard reply when people ask how I'm doing is that I'm alive and that's all that matters. Of course, I also tell them that I'm still getting

gold stars from the doctors. I try to keep busy and not to let my imagination run wild. Sometimes just writing about my experience helps. It's hard for my husband and I to talk about what is happening in my life, but it does help to let him know what I'm thinking. I know he will never stop worrying, but if we can talk about it he might ease up a little.

I have been very lucky. Many people have helped me even though I didn't know them and they didn't know me. The band my husband plays with held 2 benefits to help us with the financial problems. Some people helped me just because they knew and liked the band. I have very much surprised the doctors because they didn't think I would live this long. I took a trip to Florida to visit my parents about 1 month after leaving the nursing home. We are making that an annual event. The best thing to happen out of all this is that my brother's son is going to try to quit smoking. He knew about my cancer, but had never seen my physical problems or seen me try to eat. Once he saw that, he told me that he was going to quit. I know how hard it is, but it is something that could save you from having to live like me. It could even save you from certain death. Because of a stupid decision many years ago, I cannot live a normal life. I know that the cancer will return because that's the type of cancer it is. When and where in my body it comes back is anybody's guess. I do know that I will die earlier than I ever expected to . . . maybe even before my parents who are in their late 70's. The nursing staffs at both hospitals and the nursing home treated me like I was part of their family not just some patient they had to take care of. When I went to the hospital gift shop in search of a Christmas present for my husband, the lady there even wrapped it for me and she did it for nothing! She didn't have to, but it was pretty evident that I was a patient (I was dragging around the IV pole and tubes with me) and had no way of doing it myself.

One day while I was in the oncology radiation waiting area, I spotted a plastic card. The author was a man who describes himself as a long-time cancer patient and a skeptic. Basically it was a set of 10 paragraphs to help you through a serious illness. You have a right to have whatever feelings you have. You can cry and you can even give up when you know you can't go any further. Focus on one thing each day, not all of your problems. You are not a worthless person and you deserve to be helped. Just because people do not respond to you, it does not mean they are not rejecting you, they just don't know what to say or do. Don't expect so much from yourself. It also alludes to the fact that there just might be a higher being with a plan for you. Sometimes, I would do something my husband felt I shouldn't do. Because he had also read this card, I could just say "I'm allowed" and he would let it go.

I was also raised in a religious environment. There were several ministers (2 were ordained) in my family and we went to church every Sunday. After I moved away from home, I was working on Sundays and I got away from going to church. But I never gave up my beliefs. I always knew that God had a plan for me and would be with me to the end. I have since gone back to the church. I have been included on a lot of prayer group lists all over the country. These people didn't know me but because they knew someone who did, they were willing to pray for me as well as my family. I was blessed with many friends who prayed for me and helped my husband deal with the situation. My religious beliefs helped me keep going when I really felt like giving up. I believed in God and I

knew that all I had to do was put myself in His hands. I have to admit that I wondered how God could let this happen? What had I done to deserve this? I've still been unable to answer that question. Only God knows what His purpose is for my life. I do know that without the doctors' intelligence, education, and the tools to do their jobs, my survival would not have been possible. I believe that a higher power led them to their profession. He also led scientists to the many wonderful scientific findings that led to the treatments I needed. Maybe my surviving was so that I could let people, especially the young, know what could happen if they smoke. So far that's the only reason I can come up with. I do believe that if I can help one person not smoke then what I live with is worth it. My faith in God was greatly tested. Throughout my experience I have prayed and I continue to be on many prayer group lists. I can only fight so much on my own. Doctors and scientists can only go so far. My husband, friends and family can only do so much. I needed to count on my faith to get me through. I hoped God's plan for me wasn't finished. I know that when my job on this earth is done, I will be with Him in a much better place.

The other major difficulty is financial. When you can't work, you can't make money. I get Social Security Disability benefits, but that is not even half of what I could make if I worked. The medical bills associated with cancer are astronomical. I never had health insurance since it was too expensive and I couldn't afford it. I wish I had! Now I must accept medical assistance from the state. They pay most of my medical bills. The radiation alone was \$50,000. Add to this, the many doctors visits, hospital costs, x-rays and the radiologists to read them, the CT scan and the MRI, nursing home costs, medicines, food, and various tests I need from time to time. I decided to see if I could figure out what medical assistance had paid for my treatments up to now. I have some records that I receive when I get my new medical assistance card each month. I didn't receive it while I was in the hospital or in the nursing home. I had seen a couple of bills from the hospital so I could use that information to help figure the approximate amount that they had paid. What I found was a big surprise to me. I figured that at this time medical assistance had covered approximately \$150,000. That was in just two years. They still have to pay for food and medicine and various other supplies each month. This adds approximately \$18,000 to \$20,000 each year I stay alive. Add to that the doctors I must see every 3-4 months. There are also the lab tests and x-rays that are required each year. Then, of course, I also have to consider that I will be placed back in the hospital at some point in the future. It might even include another stay at a nursing home. What the state won't pay for are the medical bills I incurred while trying to find out what my pain was from and some of the supplies I need to clean the site of my button. They also won't pay housing, normal living expenses and automobile costs. We lost both our cars that we were leasing. It has now been two years since I was deemed to be disabled, so now Medicare kicks in. Medicare is usually for people over 65.

I always said I would never be one of those reformed smokers who would always be on somebody's back to quit. That is very irritating to everyone. But, if I had had any idea what having cancer really meant and what I would have to live through, I might not have started smoking in the first place. I certainly would have quit smoking a lot earlier than I

did. Now smoking for teenagers is against the law in most states. Most teenagers believe that it's just a silly law. Perhaps after reading this you will understand why this law is important. It's even getting hard to go anywhere and be able to smoke. You can't smoke in an airplane, you can't smoke in public buildings, restaurants and motels/hotels have smoking and non-smoking areas or rooms, and some restaurants don't allow smoking at all. By telling my story, I hope to help at least one person decide not to start smoking and help at least one person to quit. As in my case, if you quit it may not mean that you won't get cancer, but your changes will be a lot better than if you continue to smoke. If my story doesn't convince you, go to your local hospital and visit the cancer ward or oncology department. I have also joined a local group called the Tobacco Free Coalition. They are dedicated to the education of our young people to the dangers of smoking. I have advised them that I would be willing to go to the schools and let the kids see me in person. You see it can be easy to skip what is written or pretend that it just isn't true. But, it's just a little harder to forget if you actually see what can happen. What will they think when they see me hooked up to my pump so that I can eat? What will they think when they see all the tubes? What will they think when they see my face? I always thought I was kind of cute, but not anymore. Perhaps if they can see what they might have to go through and what their life could be like, they might change their mind about smoking. It really isn't cool any more!

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Tobacco Settlement Money
(\$5.9 billion over 25 years, the first payment is to be approximately \$338 million)

Brief History of My Own Experience with Tobacco

I am 45 years old and an ex-smoker. I quit smoking 6 years ago. Three years ago I found out I had cancer of the tongue. This was treated surgically with removal of not only the cancer but a portion of my tongue as well. Then less than 1 year later I found out I had cancer at the base of my skull. I sustained the following damage to nerves: the hearing in my left ear is less than before and sometimes sounds like I'm in a tunnel, my vocal cords were affected so badly I couldn't talk for awhile and now I sound very different from before, my left eye can't blink and only closes with aid of gold weight and because of this it waters all the time; I have no feeling on left side of my face except for some minor tingling sensations and I never know when my nose is running until someone tells me; I have a drooping mouth which doesn't move or smile/frown on left side and no feeling so I don't know when I drool unless someone tells me; and I am unable to swallow anything necessitating the feeding tube system.

I began smoking when I was 15 and it was cool then. I knew people who had cancer and never smoked and those who smoked and didn't have cancer. Like most people I believed it couldn't happen to me. It happened to me 3 years after I quit smoking.

I am aware than my cancer will come back. Where in my body and when is unknown.

I am now disabled and receive Social Security Disability payments. I need medical assistance as well as Medicare Parts A and B to cover the medical expenses I have.

Statistics I Have Read About

Young children eat some form of tobacco. Most spit it out, but those who don't can be poisoned by 1 cigarette or 3 butts. This can also be fatal. I read this in the Readers Digest, News from the World of Medicine section, the December 1997 issue.

In an article in Press Gazette on February 28, 1999, the Governor states "we are spending a lot of money on the cessation of smoking in the state and we are being very successful". I am aware that Brown County and Door County were given 100 patch kits to hand out to women who were over 18 and who wish to quit smoking.

Retailers have proposed statewide standards for tobacco stings according to an article in the Press Gazette on March 10, 1999, to see who is responsible for the illegal selling of cigarettes to minors.

Another article in the Press Gazette dated March 10, 1999, states that 2 out of 5 kids, age 14-17 smoke, direct costs attributed to smoking was \$1.4 billion in 1997, and last year (1998) 7,800 people died prematurely from smoking-related diseases.

Health Insurance is too expensive for many people. According to an article in the Press Gazette on Monday, March 15, 1999, Milwaukee County has approximately 113,000 who don't have insurance. Medical Assistance helps approximately 18,000 and 12,800 are to be covered under new BadgerCare program. The article headline proclaims that it "may reach the critical limit" for health care providers. 6 hospitals in Milwaukee County say that the charity value of care was \$23 million in 1995 and last year it rose to \$38 million.

According to a study at the University of North Carolina at Chapel Hill where 50 animated feature films were reviewed, 68% had at least one character who used tobacco or alcohol. They found that 76 characters smoked and 63 drank alcoholic beverages.

The Harvard Medical School in Boston, Massachusetts, reported in the March 17th issue of The Journal of the American Medical Association that most smokers do not recognize that smoking increases their risk for cancer and heart disease. The survey also shows that many smokers continue to deny their own personal risks from smoking.

Proposals I've Read So Far

The Associated Press says that Attorney General Jim Doyle and Governor Thompson's proposals differ. Governor Thompson proposes that approximately \$47 million be spent to hire more teachers and make elementary school classes smaller and spending the "lion's" share of the money on income tax cuts. (February 12, 1999, Press Gazette)

Senator Lasee states the Governor wants "a portion of the 338 million in the tobacco settlement money for health care programs; \$500,000 to expend cardiovascular disease and cancer research, \$1 million on education programs, \$500,000 for grants to establish a smoking prevention program for women and children". (Letter received from Senator Lasee dated March 2, 1999)

The Governor wants to spend \$40.8 million on state employees' health insurance, \$92.2 million on Medicaid, \$32.8 million on BadgerCare, \$11.2 million to overhaul long-term care, and \$5.2 million on anti-smoking. (March 9, 1999, Press Gazette)

Attorney General Jim Doyle: \$130 million to treat Medicaid patient's for tobacco-related illnesses and more than \$200 million for prevention, help to kick the habit, and protect non-smokers from second-hand smoke in next 2 years. \$60 million to \$65 million a year going to the taxpayers and the rest in a trust for anti-smoking efforts. (March 10, 1999, Opinion Section of Press Gazette)

The Governor proposes spending \$35 million to BadgerCare, \$11 on Family Care (overhaul of long-term care programs), \$5 million for anti-smoking, and the rest to the general fund. (March 10, 1999, Press Gazette, In Our View)

Representative Dave Hutchison states "The dangers associated with tobacco use are clear, and I strongly believe we need to continue to work to keep people from starting to smoke and use other tobacco products." (Letter of March 17, 1999)

Uses for the Money

I believe we should use a large part of this money to assist in payment of medical bills for smoking-related health problems. In two years, medical assistance paid \$150,000 for me, and continues to pay \$10,000 per year until my death for doctor visits, supplies, medicine, and special food. The radiation treatment alone was close to \$50,000. It will cost extra for further hospitalizations and treatments.

I believe we should help those who wish to quit but need extra help to stop the damage before it's too late. Don't just hand out a few patch kits. Give counseling. Establish groups similar to AA who have been through the process to offer courage and hope. Someone to call if they need just a little extra help.

I believe we should fight smoking through better education on the dangers of smoking and how it can change your life and lead to an early death. We should do all we can to protect the future for our kids.

According to an article that appeared in the Orlando Sentinal, their legislature wants to cut how much they spend on their own no smoking projects. There has only been a small amount of change, but they have only been working at it for 1 year. I don't believe the tobacco industry built their empire in a year, and I don't think anyone would be able to tear it down in 1 year. No matter how much we spend, we will never get everyone to quit smoking, but spending a paltry

\$5 million just isn't much of an effort. Florida spent \$65 million in one year. How can anyone really believe \$5 million will have any effect at all?

Even the Surgeon General wants all states to use this money to help smokers quit and prevent children from taking up smoking. "The court cases were not about money, but about health – the health of generations of Americans, young and old, whose lives are threatened by tobacco addiction." "At a time when states are being asked to choose between school construction, tax cuts and healthcare, I would like to suggest that there can be no greater priority to public health, community health, or family health than assuring a robust and comprehensive tobacco control program in every state." "For the first time in American History, a source of funding is available to make the goal of a smoke-free generation a reality." These comments were made in his speech to a conference sponsored by the National Cancer Institute.

Conclusion

I don't believe the Governor has ever smoked. If he did, he would realize the importance of getting help for those people who can't quit cold turkey. The nicotine placed into the cigarettes by the tobacco companies is truly addictive and they know it. They are spending extremely large amounts of money each year to keep people smoking. It's obvious that they don't care what medical problems are associated with their product. This country spends lots of money through the FDA to decide if a medication is okay to be used for just about everything. If it shows the least bit of a problem, then it is not accepted. What happened to cigarettes? The manufacturers show us how cool and beautiful it is to smoke but, they never tell you about the cruel addiction and what that addiction could cause. We have already made it against the law for minors to smoke. Big deal! This doesn't appear to be working at all. When the retailers have to have a way to find out who is selling cigarettes illegally, doesn't this convince you? Just because it is against the law, doesn't mean the police departments are arresting those who smoke. Kids are aware that the police departments do not take that time. Some people believe that because it isn't in cigarette form then it can't hurt you. Chewing tobacco is just as lethal with cigars and pipes not too far behind. It appears that our only defense is education. This takes more than just a few pamphlets and caution labels on cigarettes. Have you ever seen anyone read one of those labels? It is still legal to advertise smoking products. Just recently I saw two large ads in the Green Bay Press-Gazette that were impossible to miss. We have other programs to help those addicted to drugs so why not those who are addicted to nicotine.

This country appears to be worried about the future. We fight for the ecology and we fight for our kids' education. If we don't stop the kids from

smoking, drinking, sniffing all kinds of chemicals and taking drugs, what will the future be? Do we really want lower taxes at the expense of our kids and their future? The Governor wants to spend \$515 million on "Stewardship 2000" to acquire land for state parks and recreational areas yet is only willing to spend \$5 million on anti-smoking programs. Perhaps this \$515 million would be better spent on the graveyards that will be needed for those who will die from smoking-related diseases.

This money came from tobacco, it should go back into tobacco related matters. The court obviously felt that the tobacco companies did a bad thing and now they should pay for what they did to our society. Part of the evidence in this case was the financial difficulties faced due to the health problems. The main part of the case was about the health problems associated with smoking. I believe the Court meant for this settlement money to be used with regard to tobacco, not taxes. I think we should do like we did with the welfare system. Show other states that this money should be used to fight tobacco like it was meant to do. Smoking is a national problem and I believe that the fight needs to begin in each State. Wisconsin should help set an example of what should be done with this money and what can be done to battle the smoking issue and the health problems it causes.

I don't have kids, but we owe it to the future generations to do something about the problems associated with smoking. It will take a major effort by everyone. No matter how much we spend we will never get everyone to quit. But what about the young people? Do we really want them to live with the effects of smoking and condemn them to an early, painful death? I certainly don't want anyone to have to live like me. We have the funds at our disposal now so why not take advantage of this once-in-a-lifetime opportunity to make a difference.

Sue Judy
1707 Delaware Street
Sturgeon Bay, WI 54235
(920) 743-8378

To Rude, Welch
Robson, Brestka

22 March 1999

**TO: Members of the Health Committee
Wisconsin State Senate**

**FROM: Patricia Finder-Stone, MS, RN
-Wisconsin Nurses Association
-Wisconsin Council, American Cancer Society**

**RE: Support for the TRUST Campaign's efforts to use tobacco
settlement dollars to fund tobacco prevention efforts**

Chairman Moen, Members of the Health Committee -

My name is Patricia Finder-Stone. I am a registered nurse. I am here today representing the American Cancer Society, as well as the Wisconsin Nurses Association, and the Northeastern WI District Nurses Association. And I am also an individual who lost both parents and only sis to what I call "smoking suicide."

I appreciate the opportunity to speak with you today. I am speaking in support of the TRUST Campaign, Tobacco Reduction Using the Settlement.

You are facing a monumental policy decision as you consider how to allocate the dollars to be paid to Wisconsin from the tobacco settlement. Of course it may be tempting and politically popular to talk of tax cuts, highway improvements, and the like, but please don't forget the money is coming from the tobacco industry for financial damages. Wisconsin taxpayers, for years, have been paying billions of dollars to treat tobacco-related diseases of Medicaid recipients. In fact, tobacco addiction costs the people in Wisconsin \$1.3 billion **each and every year** in increased health care, health insurance, and medical costs. It would seem to be terribly hypocritical, therefore, to divert settlement funds **from** purposes which would reduce tobacco use to general purpose funds. The intent of the settlement is to right tobacco's wrongs, **from the past and for the future!!** And a recent survey has reflected that 89% of Wisconsin taxpayers want settlement dollars used for prevention **over any other purpose.**

I am embarrassed for our state that Governor Thompson has proposed **only \$4 million** over the next biennium, less than 1.5% of the \$338 million settlement on efforts related to tobacco. That's the **lowest of any** of the states receiving tobacco funds. Yet Wisconsin youth hold the dubious distinction of having a smoking rate **higher** than the national average.

Your ethical responsibility is to take this once-in-a-lifetime opportunity to focus on consistently funded, comprehensive, science-based prevention efforts to bring down smoking rates.

You've heard the figures. Nothing kills like tobacco. Each day in WI, 22 people die from tobacco-related illnesses, that's 7300 every year, seventeen percent of all deaths in Wisconsin!! Each year we fork out \$1.4 billion for tobacco-related diseases. Wisconsin children become smokers more often than do other children throughout the nation, and right now over 117,000 kids under the age of 18 will die prematurely due to their smoking addiction. Sixty youngsters start smoking every day and health experts predict that 20% of them...that is one third of those who start...will die from illnesses related to smoking!!!

The TRUST proposal uses only half of the total settlement funds...with \$25 m. recommended for counter advertising and public education, \$22 m. for cessation services, \$8 m. for tobacco-related research, and \$25 for community based programs

We urge that the integrity of the administrative structure be protected by an independent oversight body, with members appointed by the Governor and the Legislature. It would make funding recommendations based on best practices and research findings from across the nation, and would coordinate programs with partnerships of the many groups in the state that are addressing the implications of tobacco use.

Reducing tobacco use is the only way to reduce the burden on our taxpayers and to save many many lives!!!

Thank you for your attention.

T · R · U · S · T



Saving Dollars ♦ Saving Lives

What is the T · R · U · S · T Campaign?

The TRUST campaign stands for **Tobacco Reduction Using the Settlement**. Standing behind this campaign are the citizens of Wisconsin who are joining together across the state in support of funding for statewide, comprehensive programs and services that will reduce the addiction, disease, disability, and premature death caused by the use of tobacco. This coalition of health, medical, education, consumer, civic, business, safety, and religious groups is organized in support of the principles and goals outlined here.



Wisconsin's tobacco settlement provides a once-in-a-lifetime opportunity to significantly reduce the harmful consequences of tobacco. An investment in prevention will offset future damages and continue the commitment the State began when it filed its historic lawsuit against the tobacco industry.

The TRUST Campaign

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TRUSTCAMPAIGN@netscape.net

The **T·R·U·S·T** REQUEST

Dedicate \$80 million annually, or approximately 50 percent, of Wisconsin's settlement funds to an innovative, long-range, broad-based plan of action that will prevent and reduce tobacco use in Wisconsin. This funding level is based on state-specific recommendations developed by the National Centers for Disease Control and Prevention, Office on Smoking and Health.

TRUST Campaign: Funding Principles

Dedicate significant and recurring funding to statewide efforts that will prevent and reduce tobacco use in Wisconsin.

The historic settlement of Wisconsin's lawsuit against the tobacco industry presents the opportunity to create a permanent source of funding for programs and initiatives that will effectively reduce the loss of life, freedom, and dollars attributable to tobacco use.




Strengthen Wisconsin's commitment to prevent and reduce tobacco use.

Youth smoking rates in Wisconsin surpass the national average. While current programs represent a good first step in addressing this problem, the State now needs to bolster its efforts by instituting comprehensive, coordinated, statewide initiatives to bring smoking rates down.

Fund prevention efforts at a level that reflects the economic and societal costs that tobacco use renders upon our State.

Each year in our State, tobacco-related diseases account for 17 percent of all deaths—that's 8,000 lives lost prematurely. In 1997, it cost nearly \$1.4 billion to treat these diseases.

Fund Prevention Efforts at a level that will sustain long-term efforts to:

-  Prevent children from beginning a lifelong addiction to tobacco products.
-  Help smokers who want to quit.
-  Protect nonsmokers from the hazardous effects of secondhand smoke.



T · R · U · S · T

Tobacco Reduction Using the Settlement

Its an Issue of TRUST...

In large part, the purpose of the tobacco lawsuit was to recover damages related to smoking. Because the settlement agreement settles past *and future* claims, the responsibility now lies squarely in our hands to reduce the burden of tobacco use—and that means helping those who smoke to quit and preventing those who don't smoke or use tobacco from ever starting. Unless we act now, by investing settlement funds into innovative and effective programs to reduce and prevent tobacco use, Wisconsin taxpayers will continue to bear the future economic and health related damages of tobacco.

The FOUR CORNERSTONES...

What is a comprehensive plan to reduce and prevent tobacco use?



Tobacco use is a complex problem. There are many biological, social, and psychological reasons why people start and continue to use tobacco even after they know it is bad for them.

Because the problem is complex, there is no magic bullet that can single-handedly prevent tobacco use and its many consequences. A real solution demands a comprehensive approach that deals with the forces causing tobacco use as well as methods to resolve it.

The most effective tobacco prevention efforts strategically combine prevention, education, and treatment components consistently over time. Wisconsin's proposed plan for reducing and preventing tobacco use is comprehensive and is patterned after other state approaches that have successfully reduced tobacco use. California and Massachusetts, for example, have successfully reduced cigarette consumption and held their youth smoking rates down while other state rates have increased. Based on experiences like theirs, we have developed a blueprint for action will help turn the tide against the tobacco epidemic in our state.



T · R · U · S · T

Tobacco Reduction Using the Settlement

Please FAX this completed form to the

TRUST

Campaign

at

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Endorsement Form:

_____ YES, My organization endorses the
TRUST Campaign.

Signature and date

_____ My organization will discuss the
TRUST Campaign at our next meet-
ing which is on

We will contact you as soon as we have
discussed the Campaign and made a
decision to support it.

Name/Title

Organization

Key Contact Person

Mailing Address

City, State, Zip

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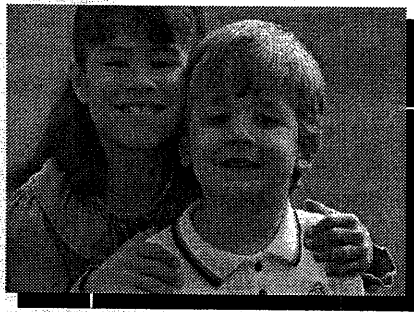
Preventing and Reducing Tobacco Use in Wisconsin: The Four Cornerstones

Advertising to Counter the Use of Tobacco

Today's youth are the most media savvy generation ever, and by age 14 they have been exposed to more than **\$20 billion** dollars of tobacco advertising.

To counter this, Wisconsin needs an advertising and media campaign to de-glamorize the image of tobacco. Such a public awareness campaign would send and reinforce powerful tobacco-free messages—creating an environment that would support, rather than contradict, school and parental efforts to deter kids from smoking.

Research suggests that it takes at least a dollar for every four the tobacco industry spends to counter pro-tobacco messages. Since the tobacco industry spends \$100 million to promote its products in Wisconsin, the State should dedicate at least \$25 million annually to fund media campaigns and public awareness initiatives aimed at preventing and reducing tobacco use. Such programs are cost-effective and proven to work.



Community-Based Programs and Initiatives

When it comes to recruiting the newest generation of smokers, the tobacco industry's toughest turf is our local communities. That's because people often come together to protect their communities—especially their children. Messages from parents, teachers, churches and the community-at-large have a great deal of influence on the young. That's why confronting tobacco use at the local level helps all of us build healthier communities.

To support community efforts, funding for local initiatives is *essential*. Through youth activities, innovative classroom education, teacher training, local cessation services, enforcement activities, technical assistance and support from local health departments, and other creative approaches, local grants can offer proven programs to meet the needs of communities. Wisconsin should invest at least \$25 million annually in community-based initiatives to reduce the burden of tobacco.

Services to Help People Quit Using Tobacco

Most people who smoke or use tobacco products want to quit, but it's difficult to do. Nicotine is known as one of the most addictive drugs around, more addictive than heroin or cocaine. Research shows that it usually takes an average of 5-7 attempts at quitting before a person is finally successful at becoming an ex-tobacco user.

Because of the state lawsuits, we now know that the tobacco industry went to great lengths to deceive the public about the addictiveness and health hazards of their product. Even while they knew the dangers, they continued to aggressively promote their products, especially to the young.

Now, it is our obligation to improve the access and availability of services that will help support and increase an individual's motivation, ability, and success at ending their addiction to tobacco products. At least \$22 million annually is required to make cessation services a legacy of the State's settlement against tobacco.

Tobacco-Related Research and Evaluation

For decades, the tobacco industry has researched how to effectively promote their deadly products. Now, it's time for Wisconsin to dedicate resources from the settlement into research that will provide us with a greater understanding of how to conquer the single most preventable cause of disease and premature death in the state.

Research and evaluation efforts will help ensure that dollars invested in tobacco prevention initiatives are put to the best possible use. Research funding will provide health and research professionals with the means to:

- effectively tailor tobacco control efforts to the needs of different communities.
- direct media and public education efforts to target audiences.
- develop appropriate community education and cessation programs.
- identify and dispel existing gaps in knowledge.

Wisconsin should invest at least \$8 million annually in tobacco related research and evaluation.

Oversight and Administration

The **TRUST** Campaign supports the recommendations of the *Koop-Kessler* committee and believes that policymakers must protect the integrity of the administrative structure that will oversee and deliver the comprehensive tobacco prevention and control initiatives funded by settlement dollars.

Tobacco use contributes to a wide range of public health problems, from asthma to impotence to heart disease and cancer. As it stands, *there is not one single health agency capable of addressing all the implications of tobacco use.*

To be effective, tobacco prevention and control efforts should be independent of the tobacco industry and structured in such a way that they will be free from political censorship or constraints.

- *Koop-Kessler Advisory Committee on Tobacco Policy and Public Health*

The **TRUST** Campaign recommends that this comprehensive program be governed by an independent oversight body, with members appointed by the Governor and the Legislature. A full range of health experts should be involved in directing tobacco control programs, including distinguished citizens, health officials, elected officials and non-profit agencies. This oversight body would make funding recommendations based on best practices and research findings from across the nation, and they will coordinate programs by forging partnerships among the many groups working to reduce tobacco use in our state.

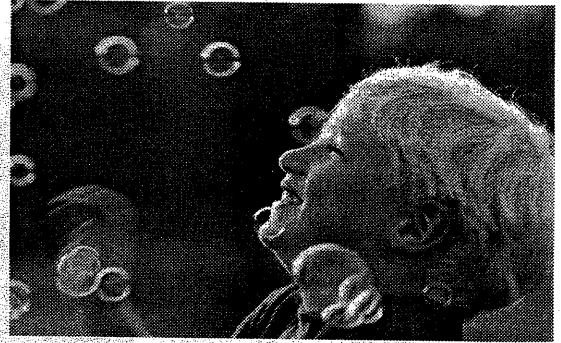


The Burden of Tobacco...

- Youth smoking in Wisconsin is higher than the national average. Nearly 2 out of 5 children aged 14-17 currently smoke. If trends continue, one-third of Wisconsin kids who smoke will die because of smoking.
- The direct health care costs attributable to smoking exceed **one billion dollars** each year.
- Seventeen percent of all deaths in Wisconsin are attributable to smoking. Last year alone 7,800 people died prematurely from diseases caused by smoking.
- There are one million smokers in Wisconsin, including 115,000 children ages 14-17.

T · R · U · S · T Supporters

American Cancer Society · American Heart Association · American Lung Association · Aurora Health Care · State Medical Society of Wisconsin · Tobacco Free Wisconsin Coalition · Wisconsin Education Association Council · Wisconsin Association of Local Departments and Boards · Wisconsin Nurses Association · Wisconsin Public Health Association ·



To join the
T · R · U · S · T
Campaign

If you would like more information about this campaign or about comprehensive tobacco control programs, please contact the

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***Independent Evaluation of the
Massachusetts Tobacco
Control Program***

Fourth Annual Report

January 1994
to
June 1997

Prepared for:
The Massachusetts Department
of Public Health

Prepared by:
Abt Associates Inc.
William Hamilton

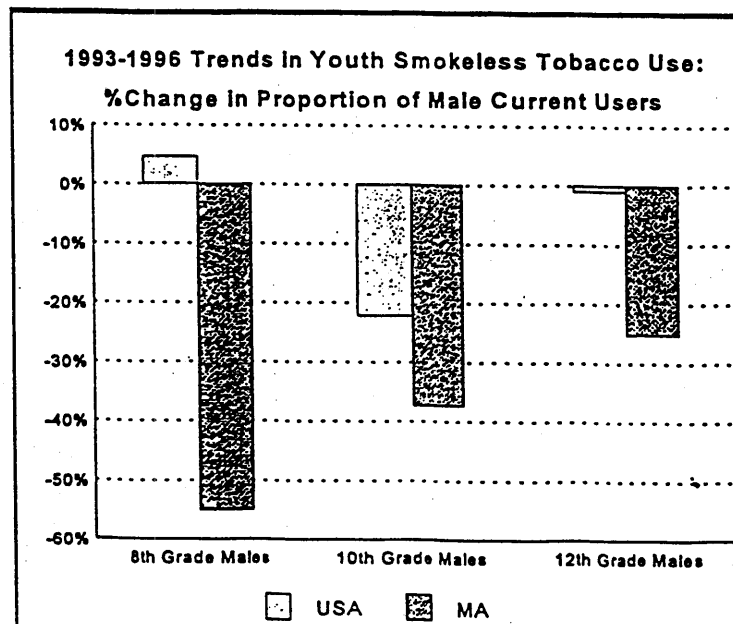
This result is consistent with research using nationwide data, which finds that states with a substantial tobacco excise tax and strong tobacco control program have experienced less growth in youth smoking than states without such programs.¹¹

As cigar smoking has become more fashionable and prevalent among adults, one might expect the problem to increase among youth as well. Indeed, 14.5 percent of Massachusetts students in grades 9-12 reported smoking cigars in the past month, as did 7.6 percent of those in grades 7-8.¹² It is likely that this rate reflects recent growth in cigar smoking, but no historical data are available for comparison.

Fewer Massachusetts teens are using "spit" tobacco. In 1996, 8.3 percent of Massachusetts males in grades 7 through 12 reported using smokeless tobacco in the last month. That number represents a major decline from the 1993 level of 15.3 percent.¹³

Smokeless tobacco usage has been declining among youth nationwide, but not as quickly as in Massachusetts. For those groups which can be compared directly, Massachusetts consistently shows a steeper downward trend than the nation as a whole.¹⁴

Higher taxes on smokeless tobacco doubtless contributed to the decline in use by Massachusetts youth. The excise tax in the Commonwealth increased from 50 percent of the wholesale price in 1993 to 75 percent in 1996. Because the wholesale price also increased somewhat during the period, the average unit retail price jumped from \$2.83 to \$4.16 from 1993 to 1996.¹⁵

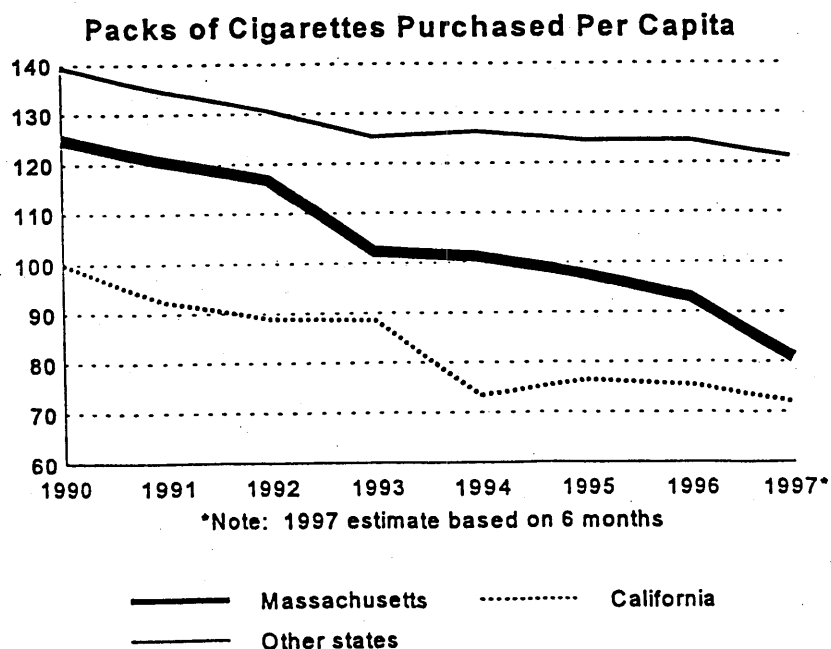


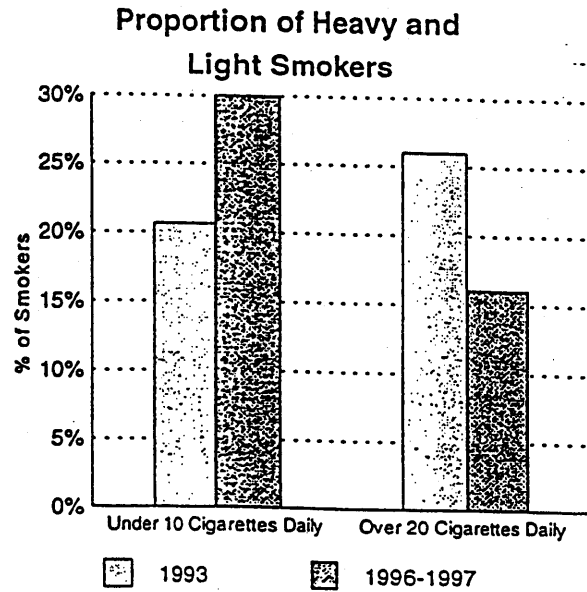
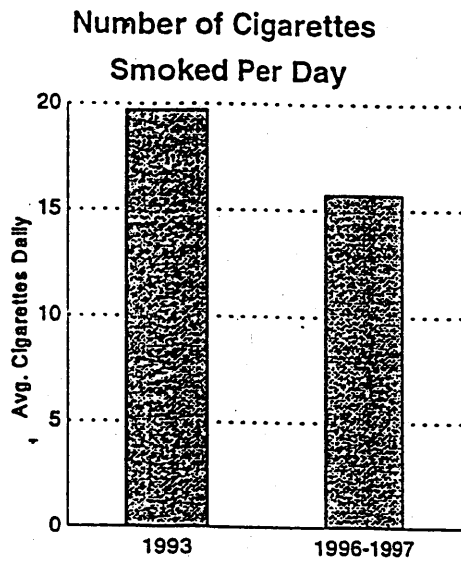
REDUCING OVERALL SMOKING

The Question 1 campaign, the cigarette price hikes resulting from the tobacco tax increases, and the efforts of the Massachusetts Tobacco Control Program have accelerated the trend toward reduced tobacco use in Massachusetts. Since Question 1 passed, tobacco sales in the Commonwealth have declined much faster than in the prior period, and faster than the national rate.

Cigarette consumption has dropped by 31 percent since 1992. Data from the Tobacco Institute show that cigarette purchases in Massachusetts in 1992 totaled 117 packs per person aged 18 or older. By the first half of 1997, purchases had dropped by 31 percent, to 81 packs per capita.¹ The steepest declines occurred in the two years following new excise taxes (1993 and 1997).

Cigarette consumption continues to fall more sharply in Massachusetts than in the rest of the nation. In California, which implemented a tobacco tax and tobacco control program in 1989 similar to the Massachusetts initiative, per capita cigarette purchases shrank by 19 percent from 1992 to 1997. Cigarette purchases declined much more slowly in the rest of the nation than in Massachusetts and California. Excluding these two states, the national consumption rate declined 7 percent from 1992 to 1997.²





Those who do smoke are smoking fewer cigarettes. Part of the decline in cigarette consumption has occurred because Massachusetts smokers are smoking less. The 1993 Massachusetts Tobacco Survey (MTS) found that adult smokers smoked an average of 20 cigarettes per day. That number fell to 16 cigarettes per day in 1996-1997, the most recent two-year period of the Massachusetts Adult Tobacco Survey (MATS).

About 26 percent of smokers in 1993 were heavy smokers—smoking more than a pack (20 cigarettes) per day. Only 16 percent were smoking at this level in 1996-1997.

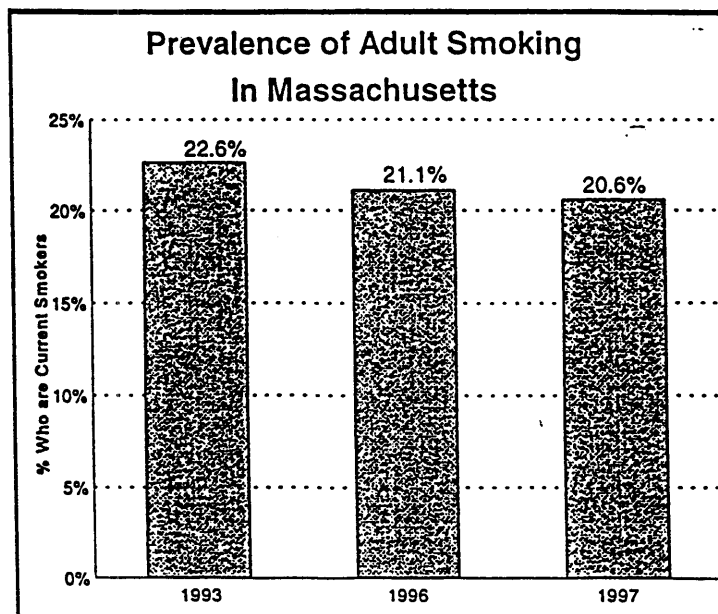
In contrast, light smokers (less than 10 cigarettes per day) increased from 21 percent of smokers in 1993 to 30 percent in 1996-1997.³

Adult smoking rates are slowly declining. The annual surveys of Massachusetts adults suggest a slow but steady decline in the proportion who smoke. The 1993 survey estimated that 22.6 percent of Massachusetts adults—about one million persons—were smokers. The 1997 estimate of 20.6 percent suggests that the number of adult smokers has fallen by about 9 percent.⁴ Most of the decline stems from a reduction in the proportion of people who smoke every day or nearly every day. The proportion of occasional smokers has remained roughly constant over the period.

This implies a reduction of 90,000 in the number of smokers. Although this figure is large enough to be important and the year-to-year pattern in the estimates is quite consistent, the measured differences to date lie within the survey margin of error.

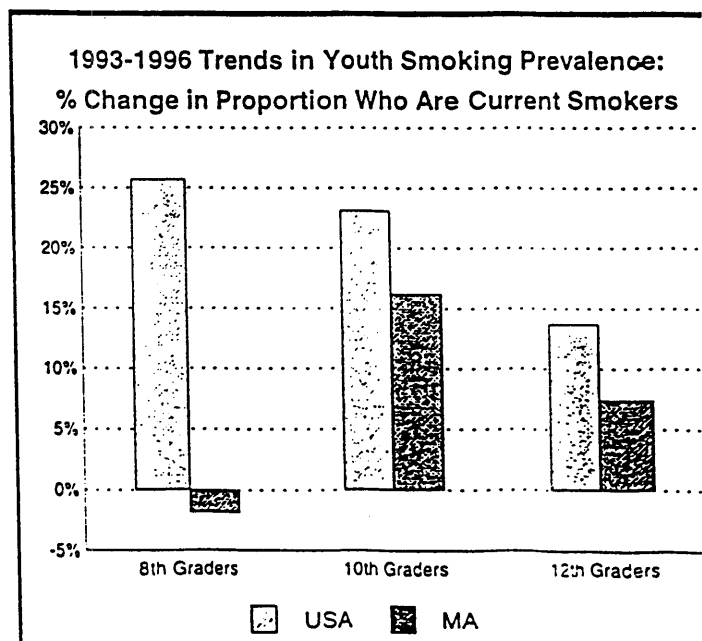
Supporting evidence of a decline in smoking comes from the Behavioral Risk Factors Surveillance Survey (BRFSS), which indicates that around 90,000 fewer Massachusetts residents

were smoking in the three years following Question 1 (1993-1995) than in the previous three years.⁵



Youth smoking climbed less in Massachusetts than elsewhere. Youth smoking rates across the nation have climbed steadily throughout the 1990s. Massachusetts participated in this trend from 1990 to 1993, but since 1993 Massachusetts youth smoking rates have stayed relatively steady.⁶ Among Massachusetts students in the 7th through 12th grades, 29.6 percent smoked in 1993 and 30.7 percent in 1996, a small difference that is within the survey margin of error.⁷

The Massachusetts time trends are more favorable than nationwide trends for all groups that can be compared directly. For example, smoking among 8th graders in Massachusetts declined slightly from 1993 to 1996.⁸ In contrast, the national 8th grade smoking rate climbed from 16.7 percent in 1993 to 21.0 percent in 1996—a 26 percent increase.⁹ Among 10th and 12th graders, smoking rates grew in both Massachusetts and the US from 1993 to 1996, but the growth was slower in Massachusetts.¹⁰



COMMISSION ON AGING, INC.

Brown County

Aging Resource Center of Brown County
formerly Brown County Commission on Aging.

300 SOUTH ADAMS STREET
GREEN BAY, WISCONSIN 54301

SUNNY ARCHAMBAULT

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DIRECTOR

***TESTIMONY BEFORE THE COMMITTEE ON HEALTH, UTILITIES,
VETERANS, & MILITARY AFFAIRS
MONDAY, MARCH 22
RON ANTONNEAU, CHAIRPERSON
AGING RESOURCE CENTER OF BROWN COUNTY***

MW

The Aging Resource Center of Brown County is responsible for representing the needs and concerns of older persons in Brown County. In reviewing the Governor's budget and the policy and values that are implied in this budget, we have real concerns about the lack of support for the existing programs that serve our county's most frail and vulnerable. While we as a people expound the merits and commitment to providing seniors and other persons with disabilities the opportunity to remain in community, the budget does not reflect these words.

While we are encouraged by the Governor's pilot projects to begin the implementation and evaluation of Family Care, this budget and policy commitment will assist long term care recipients in only nine counties. In Brown County, we now have 371 persons on the COP waiting list. These persons need assistance now. Please provide the leadership necessary to increase the support for the existing services that provide the help people need to remain in the community setting of their choice. COP, increases for Personal Care workers, nutrition, transportation, AFCSP--these programs are essential for many of our most vulnerable citizens. People needing these services can not wait for the next state budget--they need help now.

Thank you for your attention. We now need your leadership.

My name is Dr. Michael Kretz. I live and work in the Eagle River area in northern Wisconsin. With me today is Linda Kunelius, Superintendent of the Northland Pines School District. We believe some of the tobacco settlement money coming to our state should be used to teach parents, individuals, organizations, and communities of our state two things. The first is what factors need to be present in a child's life to make him or her successful; and second, what we can do in our daily lives to become better protectors of all children and promoters of their development.

The Search Institute is a non-profit national research organization located in Minneapolis, dedicated to the promotion and wellbeing of children and adolescents. They have studied the issue of which factors in a child's development lead to a successful outcome. They identified 40 factors, or assets, that are powerful protectors of young people, as well as enhancers of positive youth behavior. Using tobacco as an example, a child with 0-10 assets has a 43% incidence of smoking daily. When 31-40 assets are present, the incidence drops to 1%. This dramatic decrease in risky behavior occurs in ^{TV} categories including alcohol usage, drug usage, sexual expression, and violence. These assets also enhance school performance. Success in school (gets mostly A's on their report card) rises from 7% for those with 0-10 assets to 53% with those having 31-40.

Since 1993 the State of Wisconsin has had a Comprehensive School Health Program administered through the Department of Public Instruction and the Department of Health and Family Services. This is a wonderful multi-strategy school-based approach that recognizes how the social, emotional, and relational aspects of a child have a profound effect on how well a child learns. The teaching of assets and how parents, individuals, organizations, and communities can become asset builders throughout the state is necessary and would be a powerful addition to the current comprehensive school health program.

The State of Colorado is currently working with the Search Institute on a five year endeavor to bring the asset building message to all three million of their people. The cost is \$10 million dollars. It is our hope that this committee will want to learn more about asset building for our state, and the positive effect it would have on the education and health of our young citizens. With that knowledge, we believe you will see the value of authorizing significant tobacco money for an initiative similar to that in Colorado.

I have provided 2 handouts and an audio tape of a very special presentation by Peter Benson, President of the Search Institute. These will add clarification of the unique nature of this proposed initiative and why it is so powerful yet so badly needed.

Thank you for your kind attention.

DR. MICHAEL KRETZ

1-715-479-2638

California's Tobacco Control Program: Preventing Tobacco-Related Disease and Death

Tobacco Kills

One out of every three persons who starts smoking falls ill and dies prematurely because he or she smoked. Smoking continues to be the number one preventable cause of death in this country. Tobacco products kill over 450,000 Americans each year—more than all the deaths from AIDS, alcohol, cocaine, heroin, homicide, suicide, auto accidents, and fires combined.

Proposition 99—California Acts to Stop the Lethal Toll

In November 1988, California voters approved a ballot initiative called Proposition 99 (the Tobacco Tax and Health Protection Act of 1988) which increased the tax on each pack of cigarettes sold in the state by 25 cents. Proposition 99 earmarked 20 percent of the new revenues for health education against tobacco use.

Supported by these funds, the California Tobacco Control Program was launched in the Spring of 1990. From the beginning, the primary goals of the Program were to change the social norms of tobacco use, achieve a smokefree society, and reduce tobacco use by 75 percent before the year 2000.

A Winning Combination

The California Tobacco Control Program consists of 61 local health department, hundreds of community-based organizations, 4 ethnic networks, 11 regional community linkages programs, a state-of-the-art statewide media campaign, and nearly a thousand school districts across the state. These agencies are joined in a coordinated, multi-faceted effort to change the way tobacco and its use are perceived in the communities of California. The State's role in this effort consists primarily of providing the people of California with the tools and information they need to combat the deadly, addictive grip tobacco has on their communities.

At the State level, the California Tobacco Control Program is administered by the California Department of Health Services, Tobacco Control Section, in coordination with the California Department of Education, which administers the schools component of the program. The Tobacco Control Section administers the following program elements:

Local Program Interventions

- Local Health Departments
- Community-Based Organizations
- Statewide Ethnic Networks
- Regional Community Linkages
- Educational Resources Clearinghouse
- Statewide Multi-Language Smokers' Helpline

Media Campaign

- Multi-Media Advertising
- Public Relations Campaigns
- Technical Assistance to Community Programs

Data Analysis and Evaluation

- Analysis of Youth and Adult Survey Data
- Analysis of Cigarette Consumption Data
- Program Process and Performance Measurement

The California Tobacco Control Program is one of the most successful public health programs ever implemented. The Program's interventions, acting synergistically have been instrumental in clearing the tobacco smoke out of virtually all indoor job sites including bars and gaming clubs, and indoor public places in California. In addition, they have contributed to huge drops in cigarette consumption and the proportion of California adults who smoke. In comparison, nationally there has been little if any decline since 1990 in the proportion of adults who smoke.

The Key to Success

The key to California's extraordinary success is its "denormalization" strategy. The aim of this strategy is to change the public interpretation of tobacco. This is done by undermining the bases for regarding tobacco use as acceptable, normal, or even desirable. The denormalization strategy works by:

- ✓ **Countering the efforts of the tobacco industry to promote tobacco use.**

State, regional, and local program messages contradict the tobacco industry's claims that it does not encourage kids to smoke and that its products do not kill people and are not addictive. This includes activities to expose in every California community the pervasive presence and influence of the tobacco industry's multi-billion dollar advertising and promotional campaign to persuade kids that smoking is sexy, cool, and a very adult thing to do. In addition, the Program facilitates community activities aimed at unmasking and opposing tobacco industry efforts to block or weaken regulation of tobacco and buy influence in communities through sponsorship of community events and political contributions.

✓ **Protecting Californians from secondhand smoke.**

The Program educates the public about the serious health risks from exposure to secondhand tobacco smoke and fosters public and private policies, which protect people from such exposure.

✓ **Reducing the availability of tobacco products to children and teens.**

The Program strives to reduce the easy access children have to tobacco by carrying out public and merchant education activities, retail compliance checks, and the promotion of policies which restrict or tighten up retail sales practices, marketing, promotions, and interventions to curtail social sources of tobacco.

The denormalization strategy strives to prevent young people from using tobacco products by first changing the adult world they grow up in. As community norms change and smoking becomes increasingly inconvenient and unacceptable, more adults quit. As a result, fewer kids will be tempted to add smoking as part of their "personality armor." Teens are initially attracted to tobacco use largely because, to them, it suggests adult power and independence. As tobacco use becomes less accepted and common among adults, the allure of smoking for teens will weaken and fewer of them will want to smoke.

Gains Against Tobacco in California—Saving Lives

Californians can be proud of what has been accomplished as a result of their 1988 call for action against tobacco. The Program has had a tremendous impact on tobacco use in the state. Highlights of accomplishments include:

- In 1988, the year Proposition 99 was approved, one in four California adults smoked (26.7 percent); in 1996, close to 18 percent smoked (only one in five adults.)
- Since the passage of Proposition 99, adult smoking has declined at twice the rate it declined during the previous decade.
- More than 1.3 million Californians have quit smoking because of Proposition 99.
- Cigarette consumption in California has fallen by more than 40 percent since the passage of Proposition 99.
- An estimated 3 billion fewer packs of cigarettes were sold in California because of Proposition 99.
- 80 percent of California adults agree that tobacco advertising encourages young people to start smoking.

- 82.3-percent of California adults now agree that exposure to secondhand smoke causes lung cancer.
- Virtually all indoor workplaces in California are now smokefree, including bars and gaming clubs.
- Over 70 percent of California adults now live in households which have established a smokefree indoor air policy.
- It is now illegal in California to sell tobacco products from any vending machine other than those located in free-standing bars.
- As of January 1, 1998, billboards are no longer permitted within 1000 feet of schools and playgrounds statewide.
- Between 1994 and 1997, the proportion of tobacco retailers in California who were willing to sell tobacco products to minors decreased from 52 percent to 21.7 percent.
- 76 percent of California adults agree that tobacco retailers should need a license to sell tobacco products (just as liquor retailers need a liquor license.)

The gains against tobacco use have been won in a David and Goliath struggle against the tobacco industry. During this struggle, the tobacco companies have spent over one and half million dollars a day promoting tobacco use in California. Certainly they are not about to give up. Billions of dollars in profits are at stake. Each year their promotional budget increases and they shamelessly persist in targeting kids with hip cartoon figures, "adventure team" contests, and other clever and dazzling promotional campaigns. Their job is to get healthy young people to start using products known to be as addictive as heroin or cocaine, and 10 times as deadly.

Challenges Ahead

So California's Tobacco Control Program still has a long way to go before it has accomplished its mission. Especially challenging is the goal of preventing teens from falling victim to highly addictive properties of tobacco. If we cannot prevent this, future generations will repeat the tragic pattern of unnecessary early death due to tobacco use we see today in so many families across the state. Initially the Program succeeded in preventing further increases in teen smoking, but in 1994 the rate began to rise again. The Program's response is an expanded strategy to inoculate kids against tobacco advertisements and promotions and to step up efforts to rid communities of pervasive tobacco industry influences. In addition to local interventions, a key component of this strategy is a media campaign that provokes kids into rebelling against the efforts of the very adult and powerful tobacco industry's predatory efforts to manipulate them and pull them into a life long addiction of tobacco use.

**BARRON COUNTY
HEALTH DEPARTMENT**

Healthy Individuals · Healthy Families · Healthy Communities

**Kathleen Newman, RN, MPH
Director/Health Officer**

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March 11, 1999

MAR 15 1999

Senator Rodney Moen
Health, Utilities
Veterans & Military Affairs
PO Box 7882
Madison, WI 53707-7882

**WRITTEN TESTIMONY
ON
GOVERNOR'S PROPOSED BUDGET
3-10-99
BY
KATHLEEN M NEWMAN, PRESIDENT**

On behalf of the Wisconsin Public Health Association (WPHA) representing over 350 public health professionals throughout the State, I wish to express concern regarding the **tobacco settlement**. The Governor's proposal allocates less than 2 % of tobacco settlement monies to help smokers quit or on measures to keep our young people from taking up the deadly, addictive habit.

We urge the Legislature to take a hard look at what the Governor is proposing. By committing so few dollars to anti-smoking, the taxpayers of Wisconsin will continue to **pay out \$200 million a year in Medicaid expenses** to treat people with tobacco related illnesses. In addition, we will all continue to pay higher insurance rates and higher prices for products due to the high cost of illness care.

This is a **once-in -a-lifetime opportunity to prevent** our young people from getting hooked on tobacco, to reduce the high cost of illness care, and to prevent premature deaths due to heart disease and cancer.

The tobacco settlement is meant to be directed against the Number 1 preventable health problem. **WPHA supports the TRUST campaign and requests \$80 million be dedicated annually to the comprehensive prevention plan** outlined in the TRUST campaign.

29 APR 1996

Social Security: The Cost-of-Living Adjustment in January 1996

David Koitz and Geoffrey Kollmann
Specialists in Social Legislation
Education and Public Welfare Division

SUMMARY

To compensate for the effects of inflation, Social Security beneficiaries receive a cost-of-living adjustment (COLA) in January of each year. The Consumer Price Index for Wage Earners and Clerical Workers (CPI-W), updated monthly by the Bureau of Labor Statistics (BLS), is the measure used to compute the change. The average CPI-W for the third calendar quarter of 1 year is compared to the average CPI-W for the third calendar quarter of the next, and the resulting percentage increase represents the COLA that will become effective for the following December. The increase actually becomes payable in the following January's Social Security checks (Social Security checks always reflect the benefits due for the preceding month).

A COLA of 2.6% payable in January 1996 was triggered by the rise in the CPI-W from the third quarter of 1994 to the third quarter of 1995. This COLA, in turn, triggers identical percentage increases in Supplemental Security Income (SSI), veterans' pensions, and railroad retirement benefits, and causes other changes in the Social Security and Medicare programs. Although COLAs under the Federal Civil Service Retirement System (CSRS) and the Federal military retirement program are not triggered by the Social Security COLA, these programs use the same measuring period and formula for computing their COLAs. Their beneficiaries also are to receive a 2.6% COLA, but not until April 1996 (a delay required by P.L.s 103-66, 103-335, and 103-337).

HOW THE SOCIAL SECURITY COLA IS DETERMINED

An automatic Social Security benefit increase reflects the rise in the cost of living over roughly a 1-year period. The CPI-W, updated monthly by the BLS, is the measure used to compute the change. The average CPI-W for the third calendar quarter of 1 year is compared to the average CPI-W for the third calendar quarter of the next, and the resulting percentage increase (assuming there is one) represents the COLA that will become effective for the following December. The increase actually becomes payable in the following January's Social Security checks (Social Security checks always reflect the benefits due for the preceding month).

THE UPCOMING COLA IN JANUARY 1996

The upcoming 2.6% COLA for January 1996 became known on Oct. 13, 1995, when the BLS announced the CPI-W figure for September 1995. With release of the September index the two July - September sets of CPI-W figures needed to compute the COLA -- one for 1994 and another for 1995 -- became available.

The following analysis shows how the January 1996 COLA was computed under procedures set forth in the law.¹

TABLE 1. Computation of the Social Security COLA,
January 1996

Month	CPI-W Index Points	
	1994	1995
July	145.8	149.9
August	146.5	150.2
September	146.9	150.6
3-month average	146.4	150.2

NOTE. The reference base period for the CPI-W is 1982-1984, i.e., the period when the index equalled 100.

Source: Various BLS press reports of the CPI-W for 1994 and 1995.

Increase in CPI index points from the third quarter of
1994 to the third quarter of 1995: $150.2 - 146.4 = 3.8$

Percent increase in average CPI for the 2 quarters:
 $3.8 / 146.4 = 2.596\%$

COLA: 2.6% (by law, the change must be rounded
to the nearest tenth of a percent)

WHAT ELSE IS AFFECTED BESIDES SOCIAL SECURITY BENEFITS?

Social Security COLAs trigger increases in SSI benefits, veterans' pension benefits, and railroad retirement "tier 1" benefits. The amount of these increases is identical to the Social Security increase. Railroad retirement "tier 2" COLAs are equal to 32.5% of "tier 1" COLAs. Although COLAs under the CSRS and the Federal military retirement system are not triggered by the Social Security COLA, these programs use the same measuring

¹Under section 215 (i) of the Social Security Act.

period and formula for computing their COLAs. Their recipients also will be getting a 2.6% COLA, but it is not payable until April.²

In addition, the Social Security COLA can affect the amount of the Supplementary Medical Insurance (SMI) premium (Part B of Medicare) recipients pay. The SMI premium is a set dollar amount (\$46.10 a month in 1995 -- the 1996 amount is yet to be determined). However, the law provides that an increase in the SMI premium cannot cause the amount of a recipient's benefit to decline. Thus, for recipients with low Social Security benefits, the increase in the SMI premium can be limited to the amount of the Social Security COLA.

*discrimination
is C.P.I.W.
used to
figure C.O.L.A*

The COLA also triggers other changes in Social Security:

Taxable earnings base: The Social Security (Old-Age, Survivors, and Disability Insurance -- OASDI) taxable earnings base, i.e., the maximum amount of annual earnings subject to Social Security taxes, will rise to \$62,700, effective Jan. 1, 1996 (up from \$61,200 in 1995). This amount was not determined from the change in the CPI, but rather from another index that measures changes in average earnings levels in the economy.

Exempt amounts under the Social Security earnings test: The exempt amount of the Social Security earnings test, i.e., the maximum amount a Social Security recipient can earn from work in any year without losing some or all of his or her benefits, will rise to \$8,280 in 1996 for people under age 65 (up from \$8,160 in 1995) and to \$11,520 for those age 65-69 (up from \$11,280 in 1995). These increases also were based on the rise in the index of average earnings in the economy.

Although not triggered by COLAs, the amount needed for a Social Security "quarter-of-coverage" will rise from \$630 in 1995 to \$640 in 1996. This too is based on the rise in the index of average earnings in the economy.

²For 1984 to 1993, CSRS and military retirement system COLAs were also payable in January of each year. Under P.L. 103-66, CSRS and military nondisability retirement system COLAs were payable in April 1994. They will continue to be payable in April in 1995 and 1996, and they will revert back to January in 1997. For retirees under the Federal Employees' Retirement System (FERS), the formula and resulting increases are different.

TABLE 2. Social Security Benefit Increases Since the Beginning of the Program

Date increase paid	Amount of increase
January 1996	2.6%
January 1995	2.8
January 1994	2.6
January 1993	3.0
January 1992	3.7
January 1991	5.4
January 1990	4.7
January 1989	4.0
January 1988	4.2
January 1987	1.3
January 1986	3.1
January 1985	3.5
January 1984	3.5
July 1982	7.4
July 1981	11.2
July 1980	14.3
July 1979	9.9
July 1978	6.5
July 1977	5.9
July 1976	6.4
July 1975*	8.0
April/July 1974**	11.0
October 1972	20.0
February 1971	10.0
February 1970	15.0
March 1968	13.0
February 1965	7.0
February 1959	7.0
October 1954	13.0
October 1952	12.5
October 1950	77.0

*Automatic COLAs began.

**Increase came in two steps.

Source: Social Security Administration.

Jan 1997 - 2.9
1998 - 2.1

TABLE 3. Social Security and Medicare Taxable Earnings
Bases Since the Beginning of the Programs

Year effective	Taxable earning base	
	OASDI	HI
1996	\$62,700	All earnings ^a
1995	61,200	All earnings
1994	60,600	All earnings
1993	57,600	\$135,000
1992	55,500	130,200
1991 ^b	53,400	125,000
1990	51,300	51,300
1989	48,000	48,000
1988	45,000	45,000
1987	43,800	43,800
1986	42,000	42,000
1985	39,600	39,600
1984	37,800	37,800
1983	35,700	35,700
1982	32,400	32,400
1981	29,700	29,700
1980	25,900	25,900
1979	22,900	22,900
1978	17,700	17,700
1977	16,500	16,500
1976	15,300	15,300
1975	14,100	14,100
1974	13,200	13,200
1973	10,800	10,800
1972	9,000	9,000
1968	7,800	7,800
1966 ^c	6,600	6,600
1959	4,800	---
1955	4,200	---
1951	3,600	---
1937	3,000	---

^aThe Medicare Hospital Insurance (HI) taxable earnings base was eliminated by the Omnibus Budget Reconciliation Act of 1993.

^bThe maximum amount of earnings taxable for HI was raised from \$51,300 in 1990 to \$125,000 in 1991 as a revenue-raising measure in the Omnibus Budget Reconciliation Act of 1990. The OASDI portion went from \$51,300 to \$53,400 as a result of the automatic provision.

^c1966 was first year in which the HI tax was levied.

Source: Social Security Administration.

TABLE 4. Impact of January 1996 COLA on Benefit Levels

	Before 2.6% COLA	After 2.6% COLA
Average Social Security benefits levels:		
All retired workers	\$ 702	\$ 720
Aged couple, both receiving benefits	1,184	1,215
Widowed mother and two children	1,371	1,407
Aged widow(er) alone	663	680
Disabled worker, spouse, and one or more children	1,119	1,148
All disabled workers	665	682
Supplemental Security Income Federal payment standard:		
Individual	458	470
Couple	687	705
Source: Social Security Administration, Oct. 13, 1995.		

OTHER RELATED CRS PRODUCTS

U.S. Library of Congress. Congressional Research Service. *Payment schedule for military and civil service retiree cost-of-living adjustments, fys 1994-1999: a fact sheet.* CRS report for Congress no. 94-462 EPW, by Carolyn L. Merck. Washington, 1994.

AACT DTE:03/30/99 SSN:390-01-1201 BIC: DOC:539 UNIT:05R PG: 001
STATUS MBR YES LOU-03/30 DATA FILES YES LOU-03/30 SSACCS NO LOU-03/29
CPS NO

ACCOUNT PCOC-4 QCE-40 QCR-24 SP-M CIS-N RCC-2 ERC-77
PMT CYC CYI-1 PCEFD-06/15/1996 PCCOM-06/96 PCCR-E
PRIMARY F H CATER DOB-07/28/1911 LSPA-\$.00
PIA HIS 12/96 \$ 872.70 B K FMAX-\$1622.80T
12/97 \$ 891.00 B K FMAX-\$1656.80T ✓
12/98 \$ 902.50 B K FMAX-\$1678.30T ✓

891.00

1/3

PAYMENT PIC-A MPA-\$857.00 DOC-539 SCC-52170 RD-04/21/98 LAP-V PSC-C
TELE NO BTN-715-832-2297 BTC1-H CPND-09/96
PAYEE FRANK H CATER
ADDRESS APT 2 3413 OAK KNOLL DRIVE

EAU CLAIRE WI 54701-3036
BANK RTN-291880330 DAN-C014529005 BDCD-09/09/96
BENEFIT BIC-A FRANK H CATER SB-M DOB-07/28/1911 B DOEC-07/76 ABN-3GKY
LAF-C MBP-\$857.00 DRD-10/25/82 DOEI-07/76 DOF-06/76 LMETY-78
ENROLL HENC-I DOEH-07/76 HOC-E HPAC-\$0.00
SENC-I DOES-07/76 SOC-Y SPAC-\$45.50 SPP-00 VPAC-\$0.00

HISTORY 12/93 \$ 804.30 \$ 41.10 200 01 SR \$ 804.10
12/94 \$ 826.80 \$ 46.10 700 01 SR \$ 826.10
12/95 \$ 848.20 \$ 42.50 700 01 SR \$ 847.50
12/96 \$ 872.70 \$ 43.80 900 01 SR \$ 871.80
12/97 \$ 891.00 \$ 43.80 200 01 SR \$ 890.80
12/98 \$ 902.50 \$ 45.50 000 01 SR \$ 902.50

~~902.50~~
95.50

+++ TRANS UPDATED THRU 03/30 +++

TRANS RD-4/21/98 LAP-VY MISCOR-ZIP+4 DATA PIC-A 857.00

~~12/96~~ - 2.6 - 12/95 848.20
2.9 - 12/96 - 872.70
2.1 12/97 - 891.00
1.2 - 12/98 - 902.50

826.80

FACT DTE:03/31/99 SSN:390-01-1201 BIC: DOC:539 UNIT:024 PG: 002+

12/87 \$ 639.80 B K FMAX-\$1189.30T ELY-78 IME-\$ 00
12/88 \$ 665.30 B K FMAX-\$1236.80T ELY-78 IME-\$ 00
12/89 \$ 696.50 B K FMAX-\$1294.90T ELY-78 IME-\$ 00
12/90 \$ 734.10 B K FMAX-\$1364.80T ELY-78 IME-\$ 00
12/91 \$ 761.20 B K FMAX-\$1415.20T ELY-78 IME-\$ 00
12/92 \$ 784.00 B K FMAX-\$1457.60T ELY-78 IME-\$ 00
12/93 \$ 804.30 B K FMAX-\$1495.40T ELY-78 IME-\$ 00
12/94 \$ 826.80 B K FMAX-\$1537.20T ELY-78 IME-\$ 00
12/95 \$ 848.20 B K FMAX-\$1577.10T ELY-78 IME-\$ 00
12/96 \$ 872.70 B K FMAX-\$1622.80T ELY-78 IME-\$ 00
12/97 \$ 891.00 B K FMAX-\$1656.80T ELY-78 IME-\$ 00
12/98 \$ 902.50 B K FMAX-\$1678.30T ELY-78 IME-\$ 00

PAYMENT PIC-A MPA-\$857.00 NOB-01 DOC-539 SCC-52170 RD-04/21/98 LAP-V
PSC-C CAD-09/07/95 F/LLOA-2/4 ZDPC-137

TELE NO BTN-715-832-2297 BTC1-H CPND-09/96

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LAF-C MBP-\$857.00 DRD-10/25/82 DOEI-07/76 DOF-06/76 TOC-1

FACT DTE:03/31/99 SSN:390-01-1201 BIC: DOC:539 UNIT:024 PG: 001+
STATUS MBR YES LOU-03/31 DATA FILES YES LOU-03/31 SSACCS NO LOU-03/30
CPS NO

ACCOUNT PCOC-4 NOP-01 QCE-40 QCR-24 SP-M CIS-N LUM-03 LMM-05/98 RCC-2
ERC-77 FLI-X

PMT CYC CYI-1 PCEFD-06/15/1996 PCCOM-06/96 PCCR-E

PRIMARY F H CATER DOB-07/28/1911 LSPA-\$.00

PIA HIS	07/76	\$ 288.60	B 5	FMAX-\$	517.60T	ELY-	IME-\$	00
	01/77	\$ 300.40	B 2	FMAX-\$	548.40T	ELY-	IME-\$	00
	06/77	\$ 318.20	B 2	FMAX-\$	580.80T	ELY-	IME-\$	00
	01/78	\$ 329.60	B 2	FMAX-\$	615.10T	ELY-	IME-\$	00
	06/78	\$ 351.10	B K	FMAX-\$	655.10T	ELY-	IME-\$	00
	01/79	\$ 363.50	B 2	FMAX-\$	676.30T	ELY-	IME-\$	00
	06/79	\$ 399.50	B K	FMAX-\$	743.30T	ELY-	IME-\$	00
	01/80	\$ 402.20	B 2	FMAX-\$	747.50T	ELY-	IME-\$	00
	06/80	\$ 459.80	B K	FMAX-\$	854.40T	ELY-	IME-\$	00
	06/81	\$ 511.30	B K	FMAX-\$	950.10T	ELY-	IME-\$	00
	06/82	\$ 549.10	B K	FMAX-\$	1020.40T	ELY-	IME-\$	00
	12/83	\$ 568.30	B K	FMAX-\$	1056.10T	ELY-	IME-\$	00
	12/84	\$ 588.10	B K	FMAX-\$	1093.00T	ELY-	IME-\$	00
	12/85	\$ 606.30	B K	FMAX-\$	1126.80T	ELY-78	IME-\$	00
	12/86	\$ 614.10	B K	FMAX-\$	1141.40T	ELY-78	IME-\$	00

C.O.L.A.

6.4

5.9

6.5

9.9

14.3

11.2

7.4

3.5

3.5

3.1

1.3

4.2

4.0

4.7

5.4

3.7

3.0

2.6

2.8

2.6

2.9

2.1

111.0

22 yrs

To all whom may be Concerned,
My S.S. payments were correct
only the first five months

\$288.60

\$111.00

\$399.60

My first five payments -
C.O.L.A. dollars & cents

After adding C.O.L.A.

which was converted to
dollars and cents and then added,

C.P.I. is the difference of certain
items in living that are needed to
live, and the same are used and
compared with the last year.

If the items used are not correct
then C.O.L.A. is not correct as they
are one and the same amounts.

Changing C.O.L.A. to percentage
should be for comparing only.

I have been told at my S.S. office that
they can do nothing about this, that
it is an act of Congress on how it
is paid.

It is an error made many years
ago that you need change, as it
like a cancer (it lasts until death)

A very Concerned Citizen



Frank H Cater
3413 Oak Knoll Dr #2
Eau Claire, WI 54701-8047

The Great 1999 Budget Rip-Off

Republicans promised to cut taxes and shore up Social Security. Instead, they voted to spend, spend, spend.

**By Ralph Kinney Bennett
and Daniel Levine**

STANDING ON the noisy floor of the House of Representatives last October 20, Rep. Tom Coburn (R., Okla.) felt sick. In the waning hours of the 105th Congress, the doctor-turned-lawmaker was about to cast his vote on a bill—H.R. 4328—that would appropriate some \$500 billion, nearly a third of the entire federal budget. Yet Coburn and his 434 colleagues were expected to pass the measure without having read it. The only copy he

saw on the floor of the House was a 40-pound stack of paper almost 4000 pages long.

Negotiated behind closed doors by the White House and Republican leaders, the budget deal represented a massive act of hypocrisy, everything Coburn had come to Washington four years earlier to fight.

President Clinton had repeatedly promised to “reserve 100 percent of the surplus—that’s every penny of any surplus—until we have taken all the necessary measures to strengthen the Social Security system for the 21st century.” So much for that

promise: the new budget blew a hole in the \$70-billion surplus. But then President Clinton has never convincingly presented himself as a campaigner against big government.

Republican leaders had vowed to protect Social Security, cut the tax burden on families and reduce waste. They abandoned their promises.

Coburn slipped his electronic voting card in the slot to record a futile "nay." The

\$750,000

bill passed 333 to 95, and the Senate approved it the next day 65 to 29. This budget, says Coburn, "makes the government bigger. It spends money out of Social Security. It claims ludicrous spending 'emergencies' and, worst of all, it has no tax cut whatsoever."

Speaker of the House Newt Gingrich (R, Ga.) lashed out at members like Coburn, calling them "petty dictators" who did not know how to "work together on big issues." Vice President Al Gore couldn't help crowing over the way the White House had trumped Congressional Republicans: "We had to roll them to get this."

Hog Wild. What happened? First, having delayed all summer, Republican leaders feared if they didn't pass a budget, President Clinton would shut down the government and pin

the blame on them, as he had in 1995. In candid interviews with Reader's Digest, Republican Senators, Congressmen and key Hill staffers also pointed to the failed leadership that allowed almost a third of the budget surplus to evaporate in the strong winds of election-eve spending.

Gingrich had already earmarked \$450 million for seven giant C-130 transport planes, even though the Pentagon had sought only one. The planes are manufactured by Lockheed Martin in Gingrich's hometown of Marietta.

Rep. Bud Shuster (R, Pa.), chairman of the Transportation and Infrastructure Committee, stuffed \$13 billion into the bill for everything from highways to water taxis. A thick slice of the budget pie went to his home state.

Senate Appropriations Committee Chairman Ted Stevens (R, Alaska) steered millions to his constituents. Folks in the remote fishing village of King Cove (pop. 700) wanted to be able

\$2 million

to reach an all-weather airport 30 miles away and asked Congress to approve a simple land swap to build a new road. When the White House

objected on environmental grounds, Stevens grabbed a \$38-million package for King Cove, including \$15 million for improvements to the village's own tiny airstrip. Local government

administrator Robert S. Juetner is "habbergasted." He's not sure how \$15 million can help the airstrip, with its high winds, few planes and there.

Democrats, of course, joined in the spending frenzy. Massachusetts Sens. Ed-

\$1 million

ward M. Kennedy and John Kerry secured \$100 million for an underground highway project in Boston. Even Sen. Robert Byrd (D, W.Va.),

the legendary "Prince of Pork," acknowledged that the bill was a "gar-gantuan monstrosity." But that didn't stop him from salting away \$100 million for a new prison and \$2 million for the planned National Center for Cool and Cold Water Aquaculture in Leetown, W.Va., which has received \$16 million in federal funds since 1996.

Vanity Fare. Rep. Zach Wamp (R, Tenn.) was elected in 1994 on a promise to slash spending and shrink government. "For the first time," he had declared, "we're going to do what's right." But in his race for reelection last fall, Wamp changed his tune. He teamed up with Tennessee's two Republican Senators, Fred Thompson and Bill Frist, to slip \$50 million into the final budget for the Tennessee Valley Authority (TVA), the New Deal electric-power dinosaur. They also allowed TVA to refinance \$3.2 billion of debt. Back

home, Wamp trumpeted his success as a "Doubleplay for the TVA!"

In a sly nod to his reputation as a fiscal conservative, Wamp then voted against the entire budget package. Unabashed, he explained to the *Chatanooga Times*, "You learn how the process works and you work the system to your advantage. That's being an effective legislator."

No item, it seems, was too obscure. Rep. Rick Lazio (R, N.Y.) got \$1.5 million for the Touro Law Center in Central Islip, N.Y., for "technology to bridge the gap between legal education and the actual practice of law." Rep. Joe Skeen (R, N.M.) made sure the \$5-million International Law Enforcement Academy of the Western Hemisphere would be established not in Panama, as the State Department had wanted, but in his own district.

\$5 million

As usual, millions were appropriated so members of Congress could build monuments to themselves and former colleagues. There's \$6 million for the Robert J. Dole Institute for Public Service and Public Policy, and \$1 million for the Paul Simon Public Policy Institute. In Pennsylvania, the Wilkes-Barre/Scranton International Airport gets \$11 million for improvements, with "an understanding that the airport authority is supportive of renaming this airport

for "WOOD utilization research."

after Congressman Joseph M. McDade," the recently retired Republican from Scranton.

Disappearing Tax Cuts. Meanwhile, White House negotiators were relentless. President Clinton insisted on an \$18-billion bailout of the International Monetary Fund. He got it. Clinton wanted the first \$1.1-billion down payment on his plan to hire 100,000 new teachers. He got it. And when the White House came back the next day asking for another \$100 million, Gingrich and Senate Majority Leader Trent Lott (R., Miss.) agreed to that too.

Both the President and Congress evaded spending limits by declaring "emergencies." The President, for example, included \$1.9 billion for the U.S. military deployment in Bosnia, now in its fourth year. Congressional emergencies included \$100 million for an elaborate visitors center under the U.S. Capitol.

A handful of Republican Congressmen, dispirited by the runaway spending, confronted Gingrich. In a tense meeting, Rep. David McIntosh of Indiana urged the Speaker to "at least put some tax cuts back on the table." He was turned down flat.

As the House was preparing to vote, Appropriations Chairman Bob Livingston (R., La.) rallied support. "By adopting this bill, we can show that we can govern," he said. "It is important to vote for this bill and go home to our districts to explain why we should come back." Speaker Gingrich, according to a top Republican staffer, "put out orders that this was to be treated as a victory."

But Tom Coburn did not feel like celebrating. He cast his no vote and returned to Oklahoma. "We were going to spend money we didn't need to spend, and we were going to lie to the American public," he says.

Two weeks later Coburn won re-election overwhelmingly. But Gingrich's proclaimed "American Victory" apparently did not resonate well for the Republicans in general. Instead of gaining ten to 40 seats in the House, as Gingrich had predicted, the GOP lost five.

The lower-taxes, smaller-government Republican Revolution of 1994 had clearly lost its way. Fed up, Republicans threatened to challenge Gingrich's leadership. On November 6, he resigned as Speaker.

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