

INTERSTITIAL CYSTITIS INFORMATION CENTER  
1706 BRIERY ROAD  
2556

FARMVILLE, VA 23901-

**"HOW I HEALED MY BLADDER WITH LONGERM ANTIBIOTICS  
AND VITAMIN/MINERALSUPPLEMENTS."**

AS PRESENTED TO THE NVA IC SUPPORT GROUP MEETING, 2/95 (c) RUTH KRIZ 1995. (Updated 1/01) THIS TALK WAS GIVEN WHEN JUST IC PROGRAM I WAS AVAILABLE; NOW OF COURSE THERE ARE TWO SUCH PROGRAMS AND PATIENTS CAN CHOOSE WHICH PROGRAM THEY THINK BEST "FITS" THEM.

SPEAKER: RUTH KRIZ, CPNP, FORMER VA STATE ICA COORDINATOR AND LEADER OF NVA SUPPORT GROUP FOR FOUR YEARS, KEEPS "BUSY" NOW WITH HOME SCHOOLING TWO OF HER THREE CHILDREN WHILE THE THIRD, NOW A TEENAGER, ATTENDS REGULAR SCHOOL.

INTERTWINED WITH HER TALK ARE QUESTIONS, COMMENTS AND ANSWERS FROM AND BY MEMBERS OF THE NVA IC GROUP. THE MATERIAL CONTAINED HEREIN IN NO WAY REPRESENTS MEDICAL ADVICE; MEMBERS ARE URGED TO LISTEN AND LEARN AND PERHAPS TO TRY SUGGESTIONS GIVEN AT THEIR OWN RISK. NEITHER THE NVA IC SUPPORT GROUP NOR THE ICIC ASSUME RESPONSIBILITY FOR ANY ACTIONS TAKEN BY ANY PERSON WHO READS THIS INFORMATION THAT MIGHT RESULT IN FURTHER MEDICAL PROBLEMS FOR THAT MEMBER. YOU MAY WISH TO CONSULT WITH YOUR PRIMARY HEALTHCARE GIVER.

RUTH:

I started with IC when I was 32, in 1980, and I got really sick. I had the knife-like pain and blood in the urine. I'd go into urinary retention and end up in the emergency room at 3 in the morning having to be catheterized. Nothing helped. I tried DMSO and Ditropan and a whole list of medications--I think everything but Elmiron, but I kept getting sicker and sicker and sicker.

I am going to intersperse my story with pieces I discovered that were the answers for me on getting better. I really like Marilyn's statement at the beginning on assuming responsibility for your own health. I think of the story in the Bible where Jesus turned to the paralytic and said 'Do you want to get well?' That used to hit me as being insensitive or cruel. How could you ask someone who has been lying there...Do you want to get well? But I have been talking to hundreds of IC patients all over the country for six or seven years and I discovered that a lot of people are unwilling to take responsibility for their own health. You know,--"Dr. So and So told me this and Dr. So and So told me that." Yes, well what about you? What makes YOU feel better and what do YOU want for yourself? I think that it is really key that you understand that especially with a disease such as Interstitial Cystitis a lot of doctors out there rely on outdated textbooks and they haven't listened to enough IC patients to know what works and what doesn't work. YOU have to figure out in a lot of ways what will work for YOU.

IC is not the same thing for everybody; it is a very complex disease. I looked at it as if I was declaring warfare; I wanted my life back and this bladder was controlling my life. The attacks would hit me with seemingly no connection to anything I would do. My life was unpredictable. I couldn't plan anything. I couldn't go anywhere. I lived with chronic pain for a year. One year I was very suicidal; I was very depressed. It was an awful thing to go through.

The first thing I discovered was that diet had something to do with what was going on for me. My urologist said he didn't believe that diet had anything to do with my IC, and I asked why not? He said that Dr. Hanno didn't think it had anything to do with it. Now Dr. Hanno is a respected IC researcher and on the board of the ICA. I thought about that a while, but then, I knew, for example, that I was doing fine one day until I had that Manwich for lunch and then I spent the rest of the day and the evening and half the night in the bathroom doubled over in pain. There WAS a connection there for me, and there is also a connection there for many other IC patients. There are foods/beverages we've learned over that years that are bladder irritants for IC patients and should be avoided the entire time one is attempting to heal his/her bladder: aged cheeses, alcohol, carbonated beverages, Nutrasweet, caffeine of any sort including chocolate, and spicy foods of any kind (Sp., It., Ind., Mex., etc.).

I started playing detective about what things that I ate made me worse and what things didn't seem to bother me. Then I discovered that Dr. Larrian Gillespie in California (no longer a practicing physician) had actually listened to enough IC patients to write a list of foods that bothered them in her book, and that is what I think BJ Czarapata has expanded on and the diet that you can get from her through the ICIC (1706 Briery Road, Farmville, VA 23901-2556) for \$6.50. It is a PRELIMINARY elimination diet but it gets you started in figuring out what foods might bother you; then you can use it as a "guide" afterwards. I started on that diet and I discovered that at least there was some part of my bladder I could control. (By the way, Dr. Gillespie is no longer practicing medicine; she ran into difficulties with some of her surgical claims that she could heal IC patients with a type of back surgery; they sued her for millions of \$ and she had her license in CA revoked.)

Certain foods would automatically set off an attack. I continued to have just awful flareups every month with my period. But I could almost manage the frequency and the pressure on a day-to-day basis. But I was still getting up 3 to 6 times a night and kind of functioning in this fog from sleep deprivation.

The next thing I discovered was that there were hormones and antibiotics in the grocery store meats. I figured that my damaged bladder didn't need that so I started eating only organic meat. I didn't notice a whole lot of change directly, but that was before I learned that I had to detox and get rid of a lot of junk that had been collecting in my body for years and years.

That was another piece of it for me and then after I finally got my diagnosis, I went through six months of depression. Every time I got a letter from the ICA or read articles in the paper, I

looked at this terrible disease in which women were describing how awful it was, and I would get depressed for a week afterwards.

I finally got up the nerve to go off to the National Library of Medicine and do some research. I discovered that back in the 50s a lot of the literature was referring to IC as an allergic bladder and what they did was put the patients on elimination diets. These patients discovered what their allergy foods were, and incredibly, a number of people got better when they stayed off their allergy foods. I had my blood drawn for the ELISA Act Test which checks for delayed reactions to 343 chemicals and foods and things. I was allergic to 28 items. I was surprised because there was probably a 70-80% correlation between my allergy foods and the foods that were on the IC diet. A lot of people are not allergy people but a lot of people are allergy people and don't know it. But there was a definite correlation there for me. So I stopped eating my allergy foods such as tomatoes and onions, etc., and that helped some too. Thus, another part of the puzzle.

As I stated earlier, the ELISA Act is a blood test that tests for delayed allergies as opposed to the regular allergy tests run by immunologists which detect allergies active at the moment of testing. I would eat a food and react to it three days later. There is no way you will detect that with an elimination diet. Skin tests for food allergies are IGE mediated, which means these are ones that you have immediate reactions to. They are not very reliable. The ELISA is IGG mediated which means that it is a different part of the immunoglobulin that gives you the delayed reaction. The lab which does this test is SerAmmune Lab, an 800# you can call for through Information. The lab is located in Reston, VA, but be sure to check on that location. Your doctor also should have information or be able to obtain info on this simple blood serum test. It is expensive (over \$1k at last notice), however, so at the same time you should make sure your insurance will cover the testing; the lab checks out over 350 allergens, including preservatives, certain chemicals, etc., so if you think food or other allergies play a part in your IC, you should think about having this test done.

Between the IC diet and the allergy restrictions there was not a whole lot I could eat. I was down to 103 lbs. from the pain. I was going through a lot of STRESS: we moved three times in eleven months; I had a preschooler and an infant; and we were remodeling a house. At this point I found through the IC grapevine about Dr. Paul Fugazzotto, a PhD microbiologist in Rapid City, SD. He was finding bacteria in IC patients.

That was great news to me because as a nurse I knew that if you found bacteria, you could treat it, and what I had nobody thought you could treat. I sent him my urine, praying that he would find something, and that I wouldn't be the first person IC person in which he didn't find bacteria. Lo and behold the results came back with Betahemolytic E. Coli. I began with the antibiotic Geocillin. A month later we took care of the E. Coli, but then we found I had Group D Strept which is enterococcus which I then learned was the true pathogen.

My major flareups each month stopped and I knew I was on the right track. However, I still had constant pressure and frequency and was still getting up at night. Four months later the culture

grew out *Micropeptococcus*, so what happened was, I was kind of layering bacteria. There are friendly bacteria and there are pathogenic or disease-producing bacteria. What happened was that I had a number of disease-producing bacteria in my bladder. One was keeping the growth of the other down and the other one was keeping the growth of that one down. Every time I took care of one, the next one would then start to grow. We also discovered that my husband had enterococcus (had his semen broth cultured by Dr. F.) so I was continuing to get reinfected. My husband was treated for three months with antibiotics (men who are asymptomatic usually need just a 3-month course of antibiotics). Often men are asymptomatic (without symptoms) but carry the bacteria. I caught on to this when a woman who used to come to this group had IC and she said that her ex-husband's girlfriend had IC. There was another lady in Indiana who knew another woman who had IC but died of something completely unrelated to IC. When her husband remarried, the second wife developed IC. I kept hearing these stories and thought there was something to learn here. I learned that another woman never had any problems until she had begun having sex. I know this is how some people are picking up the bacteria.

These were very tricky bacteria because they weren't growing out on a regular dry agar culture plate; they were only growing out on a broth culture medium, because they liked water. Why do you think they were growing in the urine? I was always puzzled by why they took something that liked to grow in a liquid medium and put it on a dry culture plate and then wondered why they couldn't find anything. It was logical to me but somehow the urologists think that when you say broth cultures, that you have six heads. At any rate, I started on the antibiotics, and after I cultured out the third bacteria, we switched to Augmentin. Within four days I was sleeping through the night which I hadn't done for over six years. A miracle had happened!

Q: What strength should the Augmentin be?

R: The strength is based on your weight, so it varies for different people and what their culture results are. Under 150lbs, usually the 250mg three times a day is suggested; over 150lbs. 500mg. tid can be taken. They now even have 875mg. but that amount definitely is not a usual dosage; only some very overweight patients have been given this dosage. So another big piece of the puzzle for me was getting the infections under control. IC is sort of a chicken or egg situation. Did the infection cause the disruption of the bladder wall or was there damage to the bladder wall and therefore the bacteria found a happy home? Well, in my mind, I said it didn't really matter which came first. The point is that as long as the bacteria is there, my bladder wall is never going to be able to heal. Getting that piece under control was a real long process. I stayed on antibiotics for two years which is a long time. I went the first year at therapeutic doses and the second year at a low grade maintenance dose. I had several flareups and a couple of yeast episodes even though I stayed on a strict yeast control diet and Nystatin. Since September 1991, I've been off antibiotics, and I don't even know that I have a bladder.

Q: And what do you do with your diet now?

R: I eat anything: I go out and get hot salsa; I can eat hot salsa, Chinese or Mexican.

Q: So in other words, your damaged bladder was reacting to the allergy foods and bacteria and

now that your bladder is healed, it's better.

R: Yes. But I felt there were possibly other factors that affected my damaged bladder. So I continued to find pieces of the puzzle. There was the piece that was the IC diet, the piece that was getting off my allergy foods, the piece of getting the broth culture, and getting on the right antibiotic and staying on it long enough--10 days isn't going to do it. By this point the infection had gotten into my bladder wall and was periodically shedding off into the urine, so you are not going to get any of these 100,000 colony counts in a broth culture. And the other thing that Dr. F said that made good sense to me was, is that this is fecal strept (enterococcus) from the bowel. Strept is not a normal thing to find in the urine.

You take your kid to the doctor for a sore throat and they do a throat culture. They don't look at that throat culture and count how many colonies of strept to determine whether the kid has a strept throat or not. If the kid has strept, he has a strept throat. It doesn't matter whether they have one colony or ten colonies or a hundred colonies. It is the same way in diagnosing syphilis, tuberculosis or any other pathogenic disease that is out there. If they find the pathogenic or disease-producing organism, then you have the disease. Where is it that you have to have a 100,000 colony count before you can be officially sick? That doesn't make sense. So if you find strept in the urine then that is a known disease-producing agent. Most urologists are surgeons; they are not infectious disease people and this concept seems difficult for them to grasp. (NOTE: Dr. F believes there are some individuals who may carry the enterococcus or strept bowel bacteria in their urine and be asymptomatic, but if you show enterococcus on a broth culture and you ARE symptomatic, you have IC.)

The next half of the puzzle. Here is the bladder wall. It's inflamed, the connective tissue layer is broken down, it is edematous, and there is not a nice mucous lining...you know how on the inside of your mouth you have a nice mucous lining there. Well, it is the same thing inside of your bladder, and when that is swollen, inflamed, red, bleeding and broken down, it harbors bacteria and you are not in good shape. Edematous means full of fluid, swollen. If you sit for 12 hours on an airplane, your feet will be swollen because there is extra fluid there; that is edema.

So the next piece of this puzzle, and I think this is every bit as important as anything I have said before, is the repair process. Just getting rid of the bacteria isn't going to fix the problem. You have a damaged bladder wall that has to repair. That is what I want to talk about now. You know you can get the infection under control, but if you don't heal that mucous lining and membrane and reduce the inflammation, then the bacteria are always going to have a happy home. They are always going to keep coming back.

Q: How do they get there in the first place?

R: Well, bacteria are always ascending. You have a GI tract; you have a vaginal tract. Close proximity, anytime you have a warm moist environment, bacteria will grow and spread. As a matter of fact, primary colonization for most chronic urinary tract people is in the vagina. That is why a lot of us with vaginal problems didn't respond to yeast treatment before we ever started with bladder problems. This isn't true for everybody however.

Q: Does cervicitis come in there? If the enterococcus is gone, then where is it coming from when it comes back? If the bladder is healed, why would it keep coming in there?

R: Because you have a primary colonization in the bowel or in the vagina and it keeps reinfesting the bladder. That is probably what is going on.

Q: And it just moves along on the outer surface and then in. I just wonder if there is something lymphatic going on here too?

R: I think there might be something lymphatic too.

Q: You said before that even something as simple as the way you wipe yourself after you go to the bathroom can encourage infection.

R: Yes, one must always wipe from front to back to prevent bacteria from getting back in your bladder; you can even use a bottle of water (squeeze top preferred) and use that to pour water over your pubic area each time you urinate or defecate; then wipe from front to back. You can keep this bottle right at your toilet and use it always as a further preventative.

Let's move on to repair. When Dr. Fugazzotta was in town, he and I went to the Columbia Hospital for Women in DC to see the pathologist there. The pathologist took his big box of slides of biopsy specimens from IC patients and pulled one out at random and stuck it under the microscope. We were looking at bladder walls of IC patients and Dr. F said, let's look for the bacteria. The pathologist said I think there is an oil immersion lens on this thing, but I don't know how to use it. Dr. F went down to the micro lab and got some oil and came back with it to the pathology lab. He put a drop of oil on the slide, turned to the oil immersion lens and he could see the enterococcus right then and there. So I asked the pathologist, does this tissue, the connective tissue, and the edema and the breakdown--does this ever repair? He said, well, once you get the infection under control, it can take six to twelve months or more for this to regenerate, but it does regenerate. Almost any tissue in the body will regenerate itself if it has the proper nutrients and the irritants have been removed, whether it is allergy, or foods, or bacteria or whatever is causing the breakdown.

I began to think about how were we going to get this bladder wall repaired? This became my battle cry, Repair work. I had the infection under control, but I know if I didn't repair, there would be no hope of getting rid of the infection on a long-term basis. When I had the ELISA Act test done, the person who called me with my results was a man named Hank Liers, a PhD nuclear physicist whose wife had become environmentally ill. Because of his wife's illness, he began studying health, nutrition and nutrients needed in healing. He had never heard of IC before and when he told me to drink ginger tea, I thought this man knows nothing about IC. I would be on my death bed if I drank ginger tea. So I proceeded to educate Hank and Hank proceeded to educate me and we have come to a good working relationship. He talked to our IC group a number of years ago and worked out a protocol for nutritional supplementation for patients who have IC (HPD's IC Program I; later came IC Program II as newer compounding products were developed). A lot of people are doing very well with this, even if they haven't taken antibiotics.

For me this was the healing part that I needed to get incorporated.

Next, I'm going to go through Hank's protocol. There are seven things that he recommends IC patients take (in IC Program I) and then there are a few other things that might fit your particular needs. These supplements are not found in health food stores but can be bought through Hank's IC distributor, Kay & Duane Benton, 1706 Briery Road, Farmville, VA 23901-2556. For prepared HPD orders, you can call them at 1-800-758-1494. For supplement questions, etc., call 434-315-0060 or FAX them at 434-315-0291. To talk about IC in general, they ask that you call MyraSands at 703-765-6221 who asks for a nominal donation of \$25 for her knowledge and expertise. The Bentons discount the IC Programs and many of the other supplements for IC patients; they run a not-for-profit organization as Kay has a recovered/healed bladder and wants to help others recover as well. The sales of the supplements subsidizes keeping the ICIC information part going. Neither Kay nor her husband Duane take money of any kind from the operation of their distributorship.

1) PYC-C (pick-see) - PYC-C contains pycnogenol and Vitamin C.

Q: But a lot of IC patients can't touch Vitamin C. What makes this different?

R: My guess is that most people are not allergic to the Vitamin C but they are to the corn, wheat, preservatives, binders, sugars, etc. added to the C. Some people are even allergic to the Rose Hips but in reality perhaps it may be something else in the product. A lot of things that different products come from people can react to or to the things that they use as binders and fillers. And because Hank's wife was environmentally ill, he compounded his products with a pharmacist so they would be hypo-allergenic. Hypoallergenic means that the product does not contain wheat, rye, oats, corn, barley, gluten, eggs, sugar, wax, soy, yeast, sulfates, phosphates, chlorides, fats, preservatives casein or any other milk derivatives. These are all things that you can find in regular vitamins and supplements. If you react to any one of these, my guess is that you are not reacting to the supplement itself but to one of the fillers and binders.

Now PYC-C is derived from pine bark and grape seeds. This is a buffered C. PYC stands for pycnogenol which has been studied in Europe for over 40 years. It has been better studied and documented than aspirin. It is a natural anti-inflammatory product. Great for bladders and helps to rebuild connective tissue. Pycnogenol is the only substance that I know of that rebuilds the collagen layer and helps lay down the fibers to rebuild the damage in the bladder wall caused by IC. Remember that most Vitamin C is ascorbic acid. If you have IC anything that makes your urine acid will further irritate an inflamed bladder wall so you have to keep your urine alkaline and thus you should only take a Vitamin C product that has been buffered.

Q: How many PYC-C did you take a day?

R: Six.

Q: Do you still take as many now?

R: No, I've cut back but I still take one PYC-C and one other HPD buffered C a day. So anyway, PYC-C was the first for repair. It also helps support the immune system. I believe that

one of the reasons I had all the food allergies develop was because my immune system was shot trying to fight the infections. I needed to boost my immune system so that my body could help fight off the chronic infections and get on with its life.

2) The second nutrient important for IC is POLY-DOPHILUS (or another form of acidophilus which come by many names such as Primo-, Aloe, and Aller-, etc.) Poly-Dophilus is a mixed strain of friendly bacteria. (It's been improved to now include FOS which is an enhancer "good" bacteria love to feed on.) Normally your intestines should have lots of different types of lactobacillus and friendly bacteria. Once you have been on antibiotics or have had a yeast problem, or even constipation, the flora of the normal bacterial that grows in your bowel changes. The friendly bacteria is wiped out which leaves room for fecal strept and other kinds of organisms to find a happy home. By taking the Poly-Dophilus, it repopulates the bowel with the good bacteria that it needs. It helps control disease producing bacteria. And if you have diarrhea, it will stop that or if you are constipated, it will loosen your stools; there are amounts suggested to be taken, but you need to find what amount is best for you. You cannot take too much. One person I know when she was on IV antibiotics, found it took 12 P-D a day to keep her bowels functioning without diarrhea but that was the amount she found she needed at that time.

The metabolic cycle of the Poly-Dophilus produces hydrogen peroxide. Hydrogen peroxide (H<sub>2</sub>O<sub>2</sub>) is a potent antibiotic which kills bacteria that don't like to live in the presence of oxygen. Hydrogen peroxide breaks down into H<sub>2</sub>O (water) and that extra oxygen goes around killing yeast, bacteria, viruses and keeps you healthy naturally. If you decide to stay on long-term antibiotics, you must stay on Poly-Dophilus (or another form of it). Otherwise you will probably get diarrhea and lots of yeast problems and bad bugs that will come and live in your bowel. If you consider doing antibiotics, please take Poly-Dophilus (or another form of it). If taking antibiotics, be sure to take the Poly-Dophilus an hour before or after the antibiotic doses; otherwise the two cancel each other out. Poly-Dophilus needs to be refrigerated upon opening but still works if needed to be taken with you on a trip unrefrigerated. The refrigeration just assures greater potency. One wise doctor suggested taking whatever amount of P-D needed (after you have done it the conventional way for several months and know what amount you need) as soon as you get up in the morning first thing on an empty stomach and then go on with your day. It is difficult to remember to take the P-D in between the antibiotic doses. This takes care of that but should only be done, as stated above, after you have followed the suggested supplement schedule for several months and can then determine the amount of P-D that YOU need.

Q: Did you find that in replacing the good bacteria, that you still had diarrhea, or did this take care of it?

R: I never had diarrhea. But I take Poly-Dophilus anyway because of the problem with the colonization of bad bacteria in the bowel.

3) The next supplement is MULTI TWO, a multi vitamin. Most of the multi vitamins on the

market have ascorbic acid in them which are not well tolerated by IC patients. This product has Vitamin A, B1, B2, B3, B5, B6, B12, folate, Paba, biotin, choline, buffered C, D, E, magnesium, potassium, calcium, zinc, boron, manganese, chromium, molybdenum, selenium, and another dozen cofactors. You will not find another vitamin on the market that will give you all of these good things. Most IC patients, because of the limited IC diet and because of problems with allergies, are not absorbing properly the nutrients they need. As a matter of fact when I was pregnant I took this to my Dr and said I can't take your prenatal vitamins because they have ascorbic acid. What do you think about this product? He looked at it and the ingredients and said that the Multi Two was better!

Q: What about the B vitamins in it?

R: Although Dr. Gillespie said that B vitamins do not do well with IC patients, B vitamins never bothered me personally. A number of people tend to be sensitive to them in the bladder and a number don't. Hank also has a vitamin out called MINI MULTI with lower amounts of the B vitamins which can be better for some who are just more sensitive. It has all the same things as Multi Two but reduced amounts of B. Everyone can choose which one to take according to what he/she thinks would be best for them.

Statement: The reason B vitamins cause more bladder pain in some people is because B vitamins are a precursor to epinephrine and norepinephrine both of which cause more pain to be released from the adrenals.

4) BUFFERED VITAMIN C. This Vitamin C will strengthen your capillaries. So if you have had a lot of irritation or if you have had blood in your urine at all, that is probably a sign that your capillaries and the circulation to your bladder wall have broken down, so you need the extra Vitamin C. You are not going to get the extra C on the IC diet, because you may find that the only fruits you can tolerate at first are pears and blueberries (maybe watermelon). So a buffered C product is really important because it is going to help get the nutrients to your bladder wall, which is going to help get the medication to the bladder wall. C will help everything circulation wise get to that bladder wall and help repair it. It turns out that Buffered C also helps detoxify, gets toxins out of your body and also helps the immune system and will push the urine alkaline. You can test for this by buying test tape or ordering a container or two from your local pharmacy. You use this to test your urine pH so you can regulate and keep it alkaline. You can again call Kay or Duane Benton, Hank's distributors, at 1-800-758-1494 to place orders for any of the supplements discussed here or FAX them at 434-315-0291 (also voice mail) or to speak to one of them directly about the supplements: 434-315-0060.

5) VITAMIN E (Dry E400) is an antioxidant which protects the cell membranes from free radical damage and is also important in normal hormone function. For me, my periods were the pits. I knew at least one night each month I'd be up all night long on the toilet with an ice pack between my legs trying to sleep on the bathroom floor. Vitamin E is important especially if you have a hormonal component to your IC. It also helps control your hot flashes; I use 400-800 units a day and have not had any hot flashes since beginning the E.

Response: I had a medication that I couldn't get a prescription for because the doctor didn't believe it worked; it did work but the Vitamin E worked much better. I haven't had hot flashes since I've been taking two capsules a day.

6) MIXED CAROTENES are found in carrots, beets and cantaloupe, any of your yellow, orange vegetables and stuff. Mixed Carotenes are what your body takes to make Vitamin A. That is just fine if you don't have any thyroid trouble. But if your thyroid hormone isn't working well at the cellular level, you cannot convert the carotenes to Vitamin A. You need Vitamin A for the integrity of your mucous membranes. For example, if you get a lot of mouth ulcers, that might mean your Vitamin A level is low. If you have IC the membrane inside your bladder is broken down and you may not have enough Vitamin A.

If you have food allergies, Vitamin A is needed to line the GI tract, and when that is breaking down and you get a leaky membrane, the food gets in and sensitizes you and you develop food allergies. So I think a lot of things are related and connected to the Vitamin A deficiency. You can talk to all the nutritionists in the world who say that nobody has a Vitamin A deficiency in our society. You can get into trouble if you take bunches and bunches for months and months but you're not going to do that. It is fat soluble and it will store in your liver and you can get hypervitaminatosis.

R: I think that everybody in this room has a thyroid component to their IC and I will tell you why in a few minutes.

Q: I just got diagnosed with Hashimoto's thyroiditis; is that a connection?

R: I think there is a connection there; I'll get to that.

Q: How would you know if you were becoming toxic to the Mixed Carotenes?

R: The Mixed Carotenes are water soluble so the excess flushes out of your system and as for Vitamin A toxicity, I've never seen a case of it, so I'd have to look in my medical books. At one dose a day, you're not going to get too much.

7) ZINC is deficient in most people's good diets even in our society. If you have little white spots on your fingernails you are zinc deficient. If you don't have little white spots on your fingernails you may still be zinc deficient. Zinc is a key nutrient in healing damaged tissue. If you have tissue damage and you want it to heal, zinc is the nutrient. You can take all the antibiotics in the world and you can take all this other stuff, but if you are low in zinc, you are not going to heal. Bottom line! That is why they use zinc oxide ointment for healing of sunburn.

THYROID - So at this point I had changed my diet, I had gotten on to the right antibiotic for the bacteria I was growing according to the broth culture, and I had started doing some good repair work by taking good nutritional supplements so my body would have what it needed to rebuild that bladder wall.

On to the thyroid. In the midst of all this, I was doing all the right things, I was getting better, I wasn't having major flareups, I wasn't getting up nights. Things were moving right along, and then we discovered treating my husband was very important and the second thing we discovered was this book called Hypothyroidism: An Unsuspected Illness by Dr. Broda Barnes. If you have diabetes they don't diagnose diabetes by checking your insulin level. They check whether you are spilling sugar. Which means the insulin you have either isn't enough or the insulin you have isn't working effectively on a cellular level. As a matter of fact, most diabetics have a higher than normal insulin level.

Dr. Barnes says that he doesn't care what the lab test says when they check for thyroid function. If your basal body temperature (your body temperature before you get out of bed in the morning) is too low, then it's not working on a cellular level. Circulating thyroid hormones bind with yeast, which means it's taken out of circulation and won't work well. It gets counteracted by other hormones in the body and the adrenalin and the epinephrine in your body, so if you have a high stress level in your life than that could be causing your thyroid hormone circulating to be used up before it gets to the cells. There are a whole bunch of things that can go on.

I read Dr. Barnes' book and thought maybe that was why I had four miscarriages, maybe that was why I always have dry skin and my hair was falling out and maybe that was why my bladder wasn't healing up very well and my immune system was depressed. There was all this stuff in this book and it was like reading my medical history. I went and had the blood test done and they said you are fine and I said, no, I'm not, I have all the symptoms of hypothyroidism. I wasn't just overreacting; these are not things you imagine: the four miscarriages, the dry skin and the hair falling out. It's different things for different people, just because your hair is not falling out doesn't mean you don't have low thyroid function. I always knew that I ran a low body temperature. I would take my temperature when I was trying to get pregnant: 97.1 hmmm guess I haven't ovulated. All these low temperatures are indicative that regardless of what your blood test says, the thyroid hormone is not getting to the cells to work properly.

Dr. Barnes had a diabetic patient who had ulcers that weren't healing and they put him on thyroid and they healed. So I wonder if there is a connection between Hunner's ulcers of IC and the bladder and thyroid and healing. I don't know; I would have to see a test done on that one. I sent a survey out with the IC newsletter once and then everyone I talked to who would call me for information about IC, I talked with them about their body temperature. I got up to 56 people, and I only found one person out of the 56 with IC that did not run a low basal temperature and this person had a lot of hormonal problems.

Q: What do you consider a normal temperature?

R: Before you ovulate, your temperature should be over 97.4 and after you ovulate it should be over 98. After menopause, it should be over 97.8.

Response: Kristine Whitmore's Hanneman Hospital in Philadelphia said that when they treat thyroid, the IC gets better--they've noticed.

Response: My daughter's mother-in-law had Hashimoto's thyroiditis and they put her on thyroid and she had no more IC; still doesn't today and this was probably at least 9 years ago.

Response: My doctor took my blood work and the bloodwork came back ok. But I started the thyroid just to see if it would help, but it made me dizzy and I felt weird. He said that would be an indication that I really did not need it.

Q: Did you take something for thyroid?

R: At one point I was up to 2 grains a day thyroid extract to get my temperature to come out of the basement. As I got well, I got the yeast under control. I stayed for years on the one grain a day. I decided I was going to go off of it and in six weeks I had a urinary tract infection. A month later I had another urinary tract infection. I went back to my doctor and said do you think there is a connection? He checked me out and said that all of my reflexes were hypoactive; he said I needed to go back on the thyroid. I said yes sir! That was in 1993 and I haven't had an infection since.

Q: What doctor was that?

R: Dr. Norman Levin. (Aldie, Virginia: 703-260-3484 or 327-2434) will treat your thyroid problems based on your basal temperature. Go to him with a month full of temperatures. He will treat you by your symptoms not just by test results. Different people have different norms. The bottom line is treat me, not a piece of paper.

Discussion: Dr. Gillespie checked every IC patient who came through for thyroid dysfunction and found that a third of the people who came through with IC were hypothyroid by lab tests.

Q: How much, and how expensive and does insurance cover any of the above?

R: Insurance will not cover the supplements but they are reasonable for all that they do for you! Insurance usually covers the antibiotics because they are prescription. Thyroid medication is not expensive at all.. The ELISA Act Test is expensive (\$1050) but many insurances will cover some of the cost. Check with your doctor and your insurance company as to what they might pay.

Discussion: When I submitted my claim for the ELISA Act test, I wrote a letter backing it up with documentation about IC and articles I had on showing that IC could be an allergic problem, so you may want to think about it and back it up.

R: In addition to the Barnes Basal Temperature Test, there is also the iodine test. A lot of low thyroid function is simply because you don't eat enough iodine. Especially if you have been on a yeast-free diet. You aren't eating commercial bread which has iodine in it. This test consists of taking a 99cent bottle of iodine from the drug store and painting a three inch square on your thigh. Don't wash. Twenty-four hours later if you can still see the iodine on your skin you have enough iodine in your system. Mine disappeared in two hours. My husband's was there for three days. For some people getting enough iodine in their systems is enough to jump start their

thyroid to do better.

YEAST: Anyone who has been on antibiotics or anyone who eats a typical all-American diet probably has a yeast problem. There are a number of IC patients who once they had their yeast problem addressed, they had no further IC symptoms. A number of people have gotten on prescription medicines or supplements for systemic yeast and their IC went away. Other people who were doing antibiotics were fine, their bladders flared up again and it was yeast, systemic yeast. We are not now talking about vaginal yeast where you get the vaginal itching and the white discharge. We are not talking about people even who would have any symptoms, except they are tired, or dragging or they have been on antibiotics or they have been eating sugar in their diets. One of the books on yeast says 90% of Americans have a yeast problem. Whatever the number, a lot of people out there have yeast problems that need to be addressed.

Q: How can you tell if you have systemic yeast?

R: There are actual tests for it; one of items on the ELISA Act Test is for candida. But you can also tell when you have systemic yeast when you begin a course of Nystatin. After three days, if you have an overwhelming flu-like reaction then that is "die-off" and you have yeast. The easiest way to test for yeast problems is to get an RX for Nystatin oral tablets. The powder is cheaper if you are willing to stuff your own gel caps or you can check with your pharmacy to see if they would stuff them for you. Another friend who has IC would get tested for yeast when she thought she had it and nothing would come up and then at other times when she didn't expect it, it was found. So be just a bit wary about what yeast testing shows. Better to go with your symptoms most of the time.

Q: How much Nystatin did you begin with?

R: I started out with just 500,000 units in one tablet twice a day but someone else took one million units three times a day. The PDR recommends two tablets three times a day which is what most people need to take if on antibiotics especially.

(BJ prescribes this amount but the total tablets can vary again according to the person.) If you start out with a low dose and you feel like you have a flu reaction with that, it's the toxin that is produced from the yeast dying that makes you feel like you have the worst case of flu in your life. A pounding headache, your muscles ache, you are dragging around half nauseous, you name it--anything that is a flu-like reaction you can get from the die-off from the yeast. But don't stop taking the Nystatin as long as you are taking antibiotics. This is the easiest way to tell if you have yeast. It's better than spending \$50 on a test that may or may not be reliable.

Discussion: I started out with two tablets a day and the only thing it did was make the IC ten times worse; I was constantly in the bathroom. That's what it did to me.

R: That was the toxins; that was the "die-off."

Discussion: That's what she said, but she had me cut it back because I thought it was going to kill me before it cured me.

R: That's a very typical die-off reaction, but it does get better. Two things that help with the die-off/reaction: Flush with a lot of water and one of the detox things that sounds awful is coffee

enemas. There are lots of things for detox and a coffee enema is one of them. But when I have done some detox things and gotten the pounding headaches and the flu-like reaction, I could do a coffee enema and within half an hour would be fine. Dr. Levin is into this type of cleansing and can really address this.

The Prescription for Nutritional Healing Book has all the nutrients in it. Anyway it gives all kinds of different nutrients and what they are for. It also gives the recipes for the coffee enema and other detox methods. It's really a good book and costs usually around \$17 and is available at health food stores.

Q: When you send in your urine sample for culture and if it comes back with no yeast, do you have to worry about yeast then?

R: No, all that means is there is no yeast in your urine. That doesn't mean you don't have yeast in other places in your body.

The other thing dealing with yeast problems is that you must keep your body pH alkaline. If it is acidic, the yeast will thrive. That is another good reason besides your bladder to keep your body pH alkaline. Tums, baking soda, fruits and vegetables are alkaline performing. High protein diet, lots of meat, lots of grains make your body more acidic. There is a chart on what foods cause what reaction called "The Effects of Food on Body Chemistry" also available from the ICIC. The yeast feeds on sugar and sugar is an acid former too.

CITRUS SEED EXTRACT (now called Pro Seed Grapefruit Seed Extract): Comes in a capsule and will kill the yeast systemically and will also kill enterococcus in the GI tract. It also comes in drops. Put a couple of drops in liquid and drink it. It's yucky stuff, however. The pill does not taste bad but you have to be desperate to take the drops, in my opinion. You can also put five drops of the CSE in 5-8 ounces of water in a douche and it will take care of vaginal yeast and kill the enterococcus that might be vaginal. If you do this, be sure you are taking the Poly-Dophilus because you are killing off bad bugs and must replace them with good bugs.

Q: Does the Poly-Dophilus have milk in it?

R: The Poly-Dophilus does not, but I think some of the other brands do; it's best to use those that do not have milk or milk products in them and again are refrigerated on opening. Read the labels; some have to be refrigerated; others do not. For best use, it is recommended to refrigerate Polydophilus.

R: Have you ever heard of Tea Tree Oil from Australia? In WWI every soldier went off to war with his little bottle of Tea Tree Oil because of the melaleuca, a natural antibiotic and fungicide. So they have now come out with a douche called Nature's Cleanse. It will also take care of yeast problems and if you have bad bacteria there it will help normalize it.

Prescription products for yeast: Nystatin, Sporanox, Nizerol, or Diflucan. Nystatin is so mild they give it to preemie babies in the hospital nurseries. It does not have bad toxic problems

(other than the flu-like die-off mentioned above). The Nizerol and Diflucan are much harder on your liver particularly the Nizerol. If you have yeast in your urine, the Nystatin will not get through, but the Nizerol and Diflucan will. If you are on the Nizerol, you have to have a liver function test done every three to four weeks because it can do nasty things to a liver. So be careful with it. Diflucan is usually preferred over Nizerol but longterm use again may cause liver problems. The other thing is that yeast and fecal strept or enterococcus are synergistic which means they both encourage the growth of each other. They like to live together. If there is a consistent problem, my guess is that you have to hit both of them--not just one piece of the problem.

Q: Do you recall the dosage of Nystatin that you did?

R: I used the powder at first and I stuffed my own capsules and I did two capsules a day maintenance. If I started having any problems, felt the least bit yeasty, I increased it to four to six a day..

Q: How much was in each capsule?

R: I don't know because I stuffed them myself with the powder and I didn't measure it out. It probably was close to 500,000 units per capsule which is what now is in each Nystatin tablet.

Q: Is there anything sweet that you can eat, that is not too bad? I don't eat a lot of sweets but I have been eating a lot of hard candy lately. Does it matter whether it is fruit juice sweetened, or honey or fructose or anything like that?

R: I was just really really strict. There is a company called Sun Rider and they have a little bottle of sweetener made from Chrysanthemum flowers. When I wanted something sweet, I used a couple drops of that and that is all the sweet things I did.

Q: I know my main problem is connected to my diet. I'm good for awhile, but then I screw up and it makes me so mad. It's like you really can't eat anything.

R: I declared all out warfare. Even if I had to live like a Spartan I was going to get my life back.

Q: You can sometimes feel that living with the pain is easier than the thought of having to do this all the time and monitor everything. You can be perfect and all of a sudden it will act up. I can remember eating chicken cacciatore once and nothing happened and another time I ate a half a strawberry and was miserable for days after. I know a lot of it is discipline and all of that and how painful you are, but...

R: I got to the point where I would just look at one of those foods and could physically feel the pain. I would eat one grape and be up all night.

Response: If you keep going through this, it is like hitting your head against a brick wall. How many times are you going to hit your head before you say enough?

Q: Why do I crave sugar?

R: That is a yeast problem. One time someone told me that the foods you crave are your allergy foods. If you have a yeast problem, then you crave sweets. I would be real careful of artificial

sweeteners in any form because of the yeast and because they are bladder irritants.

PRO-GEST CREAM is made from wild yams and you say so what? If your IC flareups are strongly related to your periods, you might consider adding this to Hank's basic protocol. It also helps with PMS and has been shown that it will lead in the prevention of osteoporosis by actually replacing calcium loss in the bones. It causes your body to put the calcium back into the bones. It's a cream that you take about a quarter teaspoon a day and rub it into your abdomen and it is absorbed. Easiest thing you will ever take. He has a newer product out now called Phytoestrogen Plus, a cream made from natural herbs and it does the same thing as the Pro-Gest Cream but is less expensive. It can help PMS symptoms also. I am a very high risk person for osteoporosis; it runs in my family and I am small boned and of thin stature.

Q: What is the name of the cream?

R: Pro-Gest--also available at discount through Kay & Duane Benton, distributors for Hank. Now also Phytoestrogen Plus from herbs.

Q: How does this cream compare to say the estrogen patch or other forms of estrogen?

R: I worry. I'm biased because one of my friends just went through a hysterectomy for stage three cancer and twelve weeks of radiation which destroyed her GI tract. She is probably going to end up starving to death from the resulting malnutrition. I believe for her that going on the estrogen is what caused her cancer. I am really biased in this situation so I cannot look at the pros and cons of the estrogen replacement therapy rationally.

Response: So the jury is still out on that?

R: I can't judge; I am too close to this person to even be able to talk rationally about it.

Response: It is a chance you take; if you have a PDR and you look under estrogen, there will be about 20 pages listed of the side effects and carcinogenic possibilities.

R: There are some trace minerals that are also important here. Studies have shown that IC patients are deficient in Silica which is essential in connective tissue building. There are probably other trace minerals that we are deficient in also. Silica comes in capsules and yucky liquid. There is also hydrogen peroxide therapy which is actually done by IV and is known to be helpful for some IC patients. (Dr. Levin does these.)

Response: One of our former members did the hydrogen peroxide and it improved her situation so much, it was amazing.

R: Yes, and another of our members is doing it and doing very well with it.

R: Additionally, there is homeopathic medicine. I am still doing the strept remedy; however, the jury is still out on that. I used to get little paper cuts and nicks and stuff all the time and every month or so I would go on Keflex because these cuts would be infected. I did the staph remedy

in August 1993 and I have not had a skin infection since. Kay Benton has had feedback from an IC person who takes Poly-Dophilus and Pro Seed capsules and has not had further staph infections. There are herbs and a handbook on herbal healing which you may be familiar with. I was leafing through here and saw there was one specifically for urinary strept and staph called Usnea. A friend of mine who is no longer doing the antibiotics but who is still having strept in her urine tried Usnea and within two days was better. You take a couple drops in water and drink it.

R: COUNSELING: I also had counseling. If I wasn't crazy before I had this disease, I was after. Chronic sleep deprivation and exhaustion from pain doesn't bring out the best in anyone. When you have a chronic illness, the perception of your world gets very small and the perception of your needs gets very large. Emotional baggage from your past gets very heavy and friends and family burn out trying to meet your emotional as well as physical needs. Get help. See a therapist. I know there are others in the group who are also seeing people and I would really recommend it. It is a lot to deal with by yourself and your friends and family can be really supportive but don't burn them out.

Boost your immune system (HPD's Garlic One-a-Day odor free is helpful), thyroid, N-A-C (HPD's powerful antioxidant for healing mucous membranes), which we don't have time to talk about, echinacea and goldenseal, detoxing and liquid chlorophyll. Green Vibrance (also through the ICIC's HPD) is very good for trace minerals, as well as nutrients and detox. Detox teas can be helpful (at your healthfood store or 1-800-DETOX). There is a procedure for a liver flush I could talk to you about. Fibromyalgia is now also being associated with IC. Hank also has a complete protocol on FM using as its main product MyoMag (a combination of magnesium and malic acid). Kay has had FM but since she began using MyoMag, she has no outward pain though the trigger spots are still there.

Response: A word of caution re MyoMag for IC patients because of the small amounts of B vitamins in it. Most people won't have any trouble with it because even the multis have some Bs in them and cause no problems; but there are always some for whom any supplement might cause a problem.

R: I have never been diagnosed with Fibromyalgia but I was getting out of bed in the morning with all my muscles just aching until I started taking MyoMag. Now I take one at night time and I don't have any more muscle problems. You can take from 1-4/day as needed. It may take awhile to begin working on your muscles so be patient. It also helps in the metabolic cycle in the ATP which puts oxygen back into the muscles and tissues.

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