

RICHARD PAUL: These days you'd probably say "There are no more taboos." All the things that used to be off-limits to talk about – They couldn't say "Pregnant" on "I Love Lucy." Menopause. Phil Donahue knocked that one down. Then in the 80s ... Dr. Ruth and suddenly there was no kind of sex you couldn't talk about right there on network radio. And what doesn't Howard Stern talk about? No more taboos. Right? Well actually there's one left. You can see it on the evening news. In between the stories about all the other things you CAN talk about. It's there. Hinted at. Suggested. Like in your mom's day. Like when they used to say "Expecting." Like they used to say "Love Act." Like they used to say "Lady's Time."

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MONTAGE OF ADS FOR DIGESTIVE PROBLEMS

RICHARD PAUL: Yeah, there's one taboo left. And wouldn't you know, it's the one I want to talk about. NEED to talk about. Because people are suffering. Horrible pain Excruciating. And embarrassment. Deep, profound embarrassment. And it's frustrating and it's confounding. And they can't get help because they can't talk about it.

KIMBERLY: I remember lying on the floor in my bedroom just staring up at the ceiling and wondering, "What is wrong with me?! "Why is my body in constant turmoil and what is wrong and why can't anyone help me?" Wondering, "Is this what dying feels like?" I felt like I was dying.

RICHARD PAUL: What is it? What's the taboo? It's your gut. Not your instinct. Your actual gut. More precisely the stuff inside it. Food. After it's left the plate. After it's passed your taste buds. When it's washed with stomach acid. Or it isn't. When it's broken down. Or it isn't. When it's converted to nutrients Vitamins, Calcium, Iron. Or it isn't. The last taboo? Digestion. Who wants to talk about digestion? It's gross. But people are suffering. You might be. Or someone you love. And there's something that can STOP the suffering. But you don't know because you can't talk about it.

MUSIC

CINDY: Celiac Disease

ALLAN: Celiac Disease

COBINA: C-E-L-I-A-C.

KATHY: Is also commonly called "Sprue." Or Celiac Sprue.

BILL: It's a gut disease.

ALLAN: An intestinal disorder

DESIREE: That causes the body to respond inappropriately when introduced to certain proteins.

Dr. KELLY: Largely components of wheat but also of barley and rye.

COBINA: Primarily wheat, rye, barley and in this country, oats.

Dr. KELLY: And their immune system attacks the food particles as though they were a virus. ~~When an individual with Celiac Disease ingests cereal proteins, their immune system is activated and "T-Cells" respond against the wheat or cereal proteins. And this results in an inflammation of the intestine that's very similar to the inflammatory response that the intestine would mount against a virus.~~

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CINDY: We have little villi in our small intestines. And they act kind of like shag carpet. And when you eat food, those little villi help to absorb nutrients from that food. And when you have Celiac Disease, those villi are damaged. They're flattened so rather than being like carpet, they're more like linoleum tile and all the nutrients you eat from your food just kind of slide on by.

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YOUR BODY THINKS IT'S
BEING ATTACKED. BUT IT'S
ONLY BEING ATTACKED BY
DONUTS. CRISPY CRÈME TO
YOU. CURSES TO ME.¶
¶

DEAN: You cannot absorb anything

KIMBERLY: When the villi are flattened then the body is not able to absorb the essential vitamins and nutrients from the food that we eat.

COBINA: You may be eating a very excellent diet and still not be getting the benefit of that diet.

MUSIC SHIFTS IN TONE

KATHY: It can cause a multitude of symptoms (up inflection)

MELISSA: It can make some people throw up.

CINDY: Stomach aches for years and years and years including diarrhea, constipation and all that really fun stuff.

LARRY: You become dehydrated and you become very sick.

DESIREE: My bones were very, very weak and very painful. I couldn't hold a pen.

BILL: And I was losing weight tremendously.

KATHY: And the anemia oh my God, the anemia!

COBINA: Of course you'll get headaches, you'll get pallor.

KATHY: Depression

MELISSA: I had horrible a rash. All the time just very itchy skin.

DESIREE: I lost an inch of my height from my spine just bending from lack of calcium. And my teeth are in pretty bad shape because the enamel on my teeth corroded or eroded because of lack of calcium.

CINDY: And infertility, which is something I know all too well.

RICHARD PAUL: Celiac Disease. You heard correctly: your body attacks wheat, barley and rye like a virus. You think it's a donut but your body thinks it's a disease. I hadn't heard of Celiac Disease either. But that didn't mean I didn't have it. You could too, by the latest estimates.

study in 2003 in the Annals of Internal Medicine said, one in 133 Americans have Celiac Disease. One-in-133! These other people whose voices you're hearing ... I met them on Celiac Disease websites. There are lots of them. See this disease is "new." Well that's not true, of course. The disease isn't new. But today it's a lot easier to diagnose thanks to a couple of breakthroughs in past few years A blood test and a new flexible scope that can put a camera deeper in your body than before.... Because it's all so 'new', a lot of people WITH Celiac know as much or more about it than their doctors. I still tell my doctors things they didn't know. But that only helps – y'know ... us Celiacs giving each other information -- that only helps AFTER you've been diagnosed. All these years, many American doctors didn't know. So they couldn't spot it.

What did the medical community think of Celiac?

COBINA: I'm a registered nurse and I'm as well-trained as any registered nurse probably and what I had heard of celiac disease is, "It's a tropical thing. Celiac Sprue happens because of some kind of parasite and yeah and by the way there's this little genetic thing, but no – nobody has it." And that's what I was taught and unfortunately I think that's what doctors are taught too.

RICHARD PAUL: One-in-133 Americans have Celiac Disease.

KATHY: Which actually -- if I'm not mistaken -- is more common than diabetes.

COBINA: More prevalent than hypertension, diabetes, a number of those other things that they call "Hidden Diseases."

DESIREE: But only about 1 in 3-5,000 are getting diagnosed.

RICHARD PAUL: One-in-133 Americans have it. But only 1/3 of those with the disease get diagnosed. One-in-47-hundred ever get diagnosed. What does that mean? You'll hear that now. Some of it won't be easy.

MUSIC ENDS. A NEW PIECE OF MUSIC BEGINS, SIGNIFYING THAT WE'RE MOVING TO A DIFFERENT SEGMENT

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COBINA: We can start way-back in childhood.

BILL: I was always sick.

KIMBERLY: I threw up frequently. My stomach always hurt.

CINDY: I had stomach aches that woke me up in the middle of the night and that took me out of my classroom and into the school nurses' office quite frequently.

KATHY: "I don't want to go to school mommy. I ate breakfast. I don't feel good."

RICHARD PAUL: The stomach pain is excruciating. Like someone lined your insides with razor blades and they're smashing against each other. We'd go out to dinner when I was a kid and afterwards I'd get in the station wagon and just have to lie down in the back because I couldn't straighten up. Or it would happen at school. Of course there's one thing WOULD relive the pain, but you couldn't do it. Not around other people. They laugh at you. They give you names like "stinky" that'd stick with you the rest of grade school. The pain came from the food not breaking down inside my guts. The villi weren't absorbing. No vitamins. No nutrition.

ALLAN: You know I just never seemed to fit in with other kids I think just because of the way I was.

KATHY: The skinniest kid on the whole planet.

DEAN: Nobody wanted to play with me, you know or want me on the team.

DESIREE: I loved to swim, but I was unable to compete in the races and that kind of thing. I also loved to dance. Unfortunately I didn't have the stamina to really pursue it.

BILL: I had broken my arm one time and broke it again the same week and went back to the doctor and he says, "You appear to be a china doll." I ended up breaking my arms over a two year period four times. I had broken my leg three times.

ALLAN: I would be told something and then -- you know -- just forget it immediately.

KIMBERLY: My head hurt often (up inflection). I had difficulty concentrating. I always felt a little better when I first woke up in the morning. But right after I ate breakfast the stomach pain would return.

DESIREE: I was very, very self conscious about my body. Because my stomach was always bloated, I always thought that I looked pregnant. I'd start out in the morning maybe a size 6 and by the end of the day I'd need to wear pants that were a size 8 or 10 because my stomach had bloated so much. My ribs would stick out. My hip bones stuck out. But yet I had a protruding belly. And I can remember being 5 and 6 years old and having kids tease me about looking pregnant.

BILL: Going to the bathroom was -- you know -- 4, 5, 6, 7, 8 times a day was normal to me.

KATHY: It was annoying and scary in a sort of a way to have to arrange everything around the bathroom uh.

MELISSA: I try really hard to act like I'm having a good time but really I just want to be in the bathroom.

MUSIC SHIFTS IN TONE

MELISSA: If I'd known about it all my life? Um

COBINA: I often do think: What might have been different for me had I had more energy

CINDY: I think I would have been much better off knowing sooner.

COBINA: I might have done all kinds of things had I not just been too, darned tired.

DESIREE: I really wanted to be a dancer.

ALLAN: And you know when you're like that you don't uh -- you know you don't go out for the football team because there's not enough of ya' there to -- to be a football player.

CINDY: I was too sick and -- so that was a huge loss for me.

DESIREE: I really felt like a major failure. (laughs) That was a tough question (laughs)

MUSIC UP AND OUT

RICHARD PAUL: The thing about Celiac Disease is ... And this is really important when you consider that it's hereditary ... The thing about Celiac Disease is: It touches EVERYTHING in your life.

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CINDY: I met my husband (laughs). My first date with him it was very romantic and I couldn't eat anything -- I had a terrible stomach ache and of course the only thing I picked at that night was bread because it seemed to me like it would have been the safest and most soothing choice. We went to this very fancy restaurant and we ordered our meals and sure enough came the stomach ache and it horrendous! And I excused myself and went to the bathroom and didn't come back for about a half-hour. And by the time I returned to the table, he's kind of looking at me, "Are you OK?" (laughs) And I said, "No, I'm not. And we need to leave and we need to talk" (laughs). And when we got in the car I tried to explain to him what my problem was and at the time I didn't know what my problem was -- I just knew that this happened a lot. Out of nowhere I'd get these horrendous stomach aches and I'd have to go to the bathroom and have to go immediately

and I'd have to go for a while and he did NOT want (laughs) to hear it! He just kept saying "Oh that's OK you don't have to tell me" and I said, "Look if you want to be in a relation with me, you need to know this." So that was my dating life with my husband. It's amazing he still ended up marrying me.

KIMBERLY: I think anyone can relate to having the flu. [I didn't understand why this one was in here. Can it be deleted?](#)

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CINDY: My first year as a freshman in college I lived down the hall from the bathroom which for a Celiac when you're not on a gluten free diet (laughs) is not a very good thing. I got to the point where -- when I had to go to the bathroom, I had to go THEN and there and NOW. And so I got to be very good friends with the kids who lived in the dorm room across from the bathroom and would often sleep on their couch 'cause I had to wake up in the middle of the night several times to use the bathroom.

COBINA: I had some years, probably 10 years when all the bowel symptoms abated. I don't know why.

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DEAN: Until I got to Vietnam. And that's -- it could have been stress there -- that's where I had severe cases of diarrhea. And the flight surgeon said "Well" -- he had these little pills and took these pills and they restricted the diarrhea but I had to quit taking them 12 hours before flying. So about 2 hours after I'd stopped taking the pills, I was back to the john on a regular basis. And I think that's more than you want to hear.

Deleted: BILL: I was in a store and I had an -- a stomach attack. I had no idea what it was from. I'm usually very careful on what I do eat. I just hit me so fast. I was gettin' ready to leave the store and the stomach hit and -- I mean -- there was NO way to get to a bathroom. I mean it just exploded. I mean -- everybody's kind of stared at me -- looked at me. I just ran out of there. I've never gone back to that store. And my wife doesn't understand why -- I've told her why recently. About a year ago. But why I will never go in that store again. I just ran out to my car, put a plastic bag over my seat and ran home. But I mean it was devastating. ¶

MUSIC UP

RICHARD PAUL: Now of course, the first thing you do You're sick, you go to the doctor. [Didn't help me. Or any of these other people.](#) By one estimate, only 6 percent of Celiacs are diagnosed by their primary care physician. Here's Dr. [First name? Kelly and title? \(Drs are a dime a dozen here at Hah-vahd\)](#) from Harvard.

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DR. KELLY: US-trained physicians appear to be less aware of the condition, less aware of the myriad of ways in which Celiac Disease can present and also apparently -- seem to be less aware of the correct pathways lead to -- uh -- either diagnose or exclude Celiac Disease.

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MUSIC IN

LARRY: They came up with all kinds of diagnoses -- all of which were wrong.

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Deleted: CINDY: I remember my parents taking me to a doctor when I was young and started complaining of stomach problems.¶

MELISSA: I had acid reflux and I had y'know, like -- oh gosh, so many things like, something about, like the way that my intestines sat in my stomach hit nerves in my legs and

KIMBERLY: When I was 5 years old, my mother who is a very kind, soft spoken person had taken me to the pediatrician once again and the pediatrician pulled her aside and told her that my problems were because of her. And that she was creating my anxiety. And that's what was giving me stomach problems. And that she needed to be a better parent. And my poor mother cried all the way home. And I cried too because I knew that my parents had nothing to do with it.

▼ CINDY: The doctors said that possibly I had a parasite.

Deleted: LARRY: One day I woke up and I was dizzy. And I walked into a wall. And the doctors put me in the hospital and they said "Ah it's in your head."¶

DESIREE: I went to a hematologist because blood work that I had had done for my lack of energy came back as positive for Blast Cells. It's one of the first signifiers of leukemia.

▼ COBINA: And I was tested and told I probably had Lupus although they could not prove it.

Deleted: CINDY: And that led to a series of many MORE tests and x-rays. And all of a sudden I went from someone who had really bad stomach aches and IBS to -- you know -- ruling out cancers and ruling out, you know chronic liver failure and really scary diseases that I had to face as a possibility for myself.¶

▼ MELISSA: I really felt like I was going crazy there for a while and all my friends just thought I was such a hypochondriac 'cause I'd be like, "I just don't feel good!" (laughs)

Deleted: KIMBERLY: I landed in the emergency room for debilitating stomach pain. And the ER physician said I had an ulcer. And I went for the follow-up appointment to my primary care physician and after ruling out an abdominal tumor, he said my gall bladder was enflamed.¶

KATHY: Now I first floated the question of Celiac Disease when I was in the Air Force. When I was 18 years old. And they said "Oh No. You're just having" They have a name for it -- "Intern's Hysteria" or something like that -- where you read about something and then you -- y'know -- think you have it and so they just put it off.

DESIREE: Every doctor sort of looked at me only through the eyes of their own specialties.

MUSIC ENDS

[Richard---this is a bit abrupt; so it doesn't sound like more litany of woes, are the symptoms progressive...the longer it is not properly treated, the more debilitating it gets? Maybe something like that would set up the next section? Because it would explain the human cost of going from dr to dr and not getting a correct diagnoses? Whaddya think??](#)

▼ KATHY: It was a horror story. A horror story.

DESIREE: Then my tongue started to swell up and would crack and I didn't know why. I uh -- you know if someone shut the lights off I was completely blind -- I couldn't see anything

Deleted: COBINA: At my very worst ...¶
¶
DESIREE: My stomach aches were incredibly bad. I was unable to go more than 40 minutes without using a bathroom. ¶

KATHY: My hair was fallin' out. I could barely see. I changed my glasses every six months and it still -- I still couldn't see.

DEAN: My wife really got scared. She says she didn't want to hear another complaint unless I went back to the doctor so I did.

BILL: And the first question out of his mouth he says, "Why you so pale?" And he did a blood test and he said, "Lookit, you're coming back tomorrow morning I want you back here with your wife and we'll finish the physical." Following morning, I came back in and he says, "I'm gonna tell ya something" he says, "And I don't know how to say this but the fact" He says, "You have every indication of full-blown colon cancer." And I says, "This can't be!" He says, "Everything is pointing to that." He says, "We need to put you in the hospital and do colonoscopy. Right away."

COBINA: And I went in to see my doctor on an urgent basis – he tried to examine me and uh there was a tremendous uh – accident. On the floor. I was dying of shame, but I think the doctor was even more mortified because somehow he probably felt that he was responsible for this. But the wonderful thing is: and I kind of cry when I say this – he said, "I'll step into the next room and see – there's a doctor here – a new doctor maybe she knows something." And this wonderful woman (starts to cry) she came into the room and she says, "Oh Duckey, I know exactly what's wrong with you." And she says "We can fix you in a heartbeat." (laughs while crying) And she had a wonderful English accent. She says, "Nothing to it. You've got celiac disease. We can fix you." Just like that (laughs while crying). And so it was fixed (laughs while crying)

▼
MUSIC UP FULL

DR KELLY: Because the condition occurs deep within the body in the small intestine, diagnoses required a sample or a biopsy of the small intestine to be obtained and looked at under the microscope to identify the changes -- the inflammation that's associated with Celiac Disease.

[Dr. Kelley, again, from Harvard University Medical School : \(I would re-identify her...because this is medical info and we need to attribute it\)](#)

And this required that the individual have what's called an "Endoscopy" which is a camera test where a small camera is placed into the mouth, through the esophagus or swallowing tube, through the stomach and into the small intestine to take small pieces of tissue for diagnoses. And obviously this is a somewhat invasive test.

[But like we said earlier, the diagnostic tools have improved..a lot:](#)

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There's been a big change recently in the way in which Celiac Disease is being diagnosed. And the big change has occurred because of the availability of a simple and non-invasive test that's quite reliable in identifying people who almost-certainly have Celiac Disease. The test is a blood test. So in essence a simple blood test has replaced an intestinal biopsy which is much more invasive. And because of that, there's been a huge increase in the numbers of individuals who are being diagnosed with Celiac Disease.

Deleted: It's still important that they be evaluated and undergo a biopsy to confirm the diagnoses. Because even though the blood test is very accurate, intestinal biopsy is still the Gold Standard for diagnoses and so that -- a Gold Standard has not been set aside but access to diagnoses has been made much easier by the new blood test.¶

DESIREE: When the doctor told me that the blood came back positive for Celiac I was in shock.

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MELISSA: And I remember thinking like, in a way "Thank God!" Like, there IS something concrete that is wrong with me. It's not all these, like phantom illnesses that you know no one knows about.

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DESIREE: And I was really grateful to have a disease (laughs) I mean it sounds so ridiculous, but it's like "Oh my God! Thank you!" You know (laughs)? Who would be grateful for having a disease? But you ARE. You're SO grateful when that moment because somebody finally says "You're not crazy."

KIMBERLY: It's a feeling of justification that -- that I'm not crazy. That's how I felt. Because my inner voice kept telling me that "Something is wrong."

RICHARD PAUL: You can actually SEE the difference. I had the blood test AND the Endoscopy doctors say that's the "Gold Standard" for diagnoses. So I've looked at "before and after" pictures of my gut. I can see the villi are back. I can see areas that were clenched like a fist that are open now. No WONDER I feel better.

Deleted: KIMBERLY: I had headaches all of the time and I never realized how frequently I was taking medication for the headaches until I went on a gluten free diet and everything completely went away. And it was just a couple weeks after -- and I realized "Gosh, I have not taken medicine for my headache!"¶

CINDY: My stomach aches were gone! I mean after living a life with stomach aches I mean there was not a day that passed where I didn't complain of something I didn't HAVE any more!

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DEAN: I told people I feel better at 75 than I did at 50. Much better.

RICHARD PAUL: Happy ending right? Well yes and no. Because the only way you keep the pain away – and all the other stuff – is go on a strict STRICT, gluten-free diet.

MELISSA: I went down, I got my gluten-free diet and I started to look through it and it just sort of wanted to cry.

BILL: I mean I just sat there in the chair going like, "OK, what do I eat now?"

DESIREE: My whole life was wheat, basically, with the occasional piece of protein thrown in (laughs)

KATHY: You can't eat the bread, the cookies, the uh all the good stuff -- cake.

BILL: I couldn't have spaghetti. I used to love spaghetti.

KATHY: Pizza Hut pizza. I mean I could have LIVED at Pizza Hut -- I could have just moved a bed into Pizza Hut, I loved Pizza Hut that much. That REALLY just killed me.

MELISSA: It's frustrating to go to a restaurant and have the waiter think that you're insanely picky (up inflection). I always just feel bad when I go in restaurants.

ALLAN: But the big thing for me was beer. I traveled to Europe 7 or 8 times to drink beer. And I was a beer connoisseur.

KATHY: The first thing I did was log into a Google search. And came up with -- within a week -- I had a working diet.

DESIREE: I surfed the 'net, looking for any kind of support that I could and I found um numerous, numerous websites.

KATHY: If you email and say "Help! I'm new! Tell me how to start this!" You get bombarded with a hundred emails from lovely, wonderful people who've been through it (up inflection)

BILL: Just learning about the foods and then finally understanding that there ARE a lot of foods out there that you CAN eat. You're not as restricted as I thought.

KATHY: All of a sudden one day you look back at what you've eaten over the past year and you'll say "Oh wow, wait a minute, with a few adjustments, I can do this!"

MUSIC CHANGES

RICHARD PAUL: As far as how you get your doctor to even listen to you if you think you have this ... go to the web. Type your symptoms in Google and add the word "Celiac". Then take the evidence to your doctor and tell him you want the blood test. That'll get you started. There are still a lot of mysteries around this disease. No one knows what triggers that immune response by the gut, that treats food like a virus. And there's no cure. No pill you can pop....However, Dr Kelly from HMS says:

KELLY: there are very many individuals who are on a strict gluten-free diet for Celiac Disease who would welcome the opportunity of taking a medication that would allow them perhaps to eat out in a restaurant and be less concerned about the possibility of gluten contamination.

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RICHARD Paul: And researchers are looking at a few approaches..treatments that would break down cereal proteins so they COULD be digested properly, or a drug that would turn-off the immune system so it doesnt fight against food proteins.

But I would predict that it'll be 5 or 10 years at the earliest before any of these research approaches are available for clinical use.

Until then, a gluten-free diet does the trick. It works. Those of us with the disease now have the tools to manage it.

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DESIREE: It's been about 4 years since my diagnoses

KIMBERLY: My challenge lies with actually dealing with the reactions of other people. I've learned that people in general, by nature tend to be more focused on the negative than the positive. And when I'm in a situation where I need to explain why I can't eat certain things, the general reaction is, "Oh that's awful!"

COBINA: Being invited to someone else's house is so often – I feel sorry for the hostess. I offer to bring things and I usually carry a few crackers in my purse.

DEAN: There's nothin' better than having a good ol' gut that feels good.

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Eating away from home¶

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DESIREE: I had absolutely no idea that you could feel this good (laughs)

KATHY: The anemia's gone. I'm not wrestling with my blood sugar all the time. The depression is gone. My eyes have straightened out. The rewards are just -- You can't even list 'em.

Deleted: MELISSA: It's frustrating to go to a restaurant and have the waiter think that you're insanely picky (up inflection). I always just feel bad when I go in restaurants.¶

BILL: I live every day you know just in happiness. Even though I know I have a disease, I'm -- I'm a healthy person.

Deleted: Well of course I'll tell ya' about the rewards.

KIMBERLY: And it's a blessing with challenges but it's certainly not a curse. And I wish people would understand that. When you've walked your entire life with a piano on your back and to have that removed -- it's just -- you feel like you're walking on air.

Deleted: KIMBERLY: I mean it's not a cliché -- the grass IS greener. The sky IS bluer. ¶
KATHY: It's like being born again, physically. ¶

MUSIC SWELLS

SPELL OUT THE NEW BREAKTHROUGHS
FLEXIBLE SCOPES
BLOOD TEST
COULDN'T GET DEEP ENOUGH IN THE BODY

But with the breakthrough, how can you make such a broad statement?

DR. KELLY: The National Institutes of Health recently organized a consensus development conference on Celiac Disease and one of the major conclusions of that conference was that there was a great need for increased education of United States physicians in the presentation, diagnoses and management of Celiac Disease and this is across-the-board, it does not just relate to specialists, such as gastroenterologists, but relates really to all physicians because Celiac Disease can present in so many different ways that really it's important for every specialist to be aware of how to recognize and diagnose Celiac Disease including, of course the primary care physician.

It sounds a bit odd to set this up as what do doctors think..and then go to a nurse. Why not a doctor?

-this needs to be verified based on our discussion

But it's important. People are suffering. And it's time to talk about it.