

## Story of CHESS:

Kathleen:

When I was first diagnosed it was, I mean like a total surprise, it's something I had never, would, never would think that going to the doctor would, ever, was going to come out being told I had breast cancer.

Ellen-

At those days, you know, if you read the books it said that you had like a 5 or 10 percent chance of living 5 years.

Chris:

I was in complete shock. I wasn't able to function other than getting up every day, getting dressed, and getting to where I needed to be. And then CHESS came into my life.

Dave Gustafson:

One of the first applications of computer technology that we engaged in, was trying to help teenagers cope with the difficulties they face as they're going through their middle and high school years. Problems such as drug abuse, and alcohol, and sexual activity and so on. We felt that if we had, if we could develop a computer system that would be available in the schools, that it might help them cope more effectively with those problems, and prevent those problems from occurring. And, we found that we failed miserably on that particular level of things. The system was used a lot, but we found that it was used by people that were already in trouble, people who were smoking and wanted to quit. And so, we found that the system, rather than being a preventative tool, seemed to be helpful in terms of dealing with problems that already existed.

Fiona McTavish

And so, about 20 years ago, we really started with CHESS with breast cancer, we had HIV, modules and other modules, but it was really HIV and breast cancer. And in breast cancer, like HIV, people had a need, so they were really, really yearning for information.

Joan:

When my surgeon gave me a choice of a lumpectomy, or a mastectomy, I didn't know what to answer, I didn't know I would be given a choice.

Chris-

I did not know the vocabulary, that went along with breast cancer, and being able to talk to doctors like I needed to. I needed that, I didn't even know where a lymph gland was.

I guess, in my own mind, and maybe I was naïve two years ago, I had a little two centimeter tumor, you're gonna cut it out of the breast, gonna have a little chemo radiation, boom, it's over, your life goes back to normal, everything's fine. Well lo and behold two years later, it didn't turn out the way I had dreamed it would turn out. Two recurrences later, and I guess I was naïve, and I'm not naïve anymore, probably due to CHESS.

Kari Wisinski-

I think breast cancer, like most cancer diagnoses when women are diagnosed, is very overwhelming, there's lots of decisions to be made and in a relatively quick time period. And so, you know, we sit down and talk with patients as their being diagnosed, and try to guide them through those decisions, but to have a resource that they can go to afterwards to answer their questions and answer them in a way that we know is, represents good data good information for those patients is really important.

Fiona McTavish-

We had computers, and it was DOS based computers at that point, and many people had never actually used computers so we would literally drive to their home, take them a computer, set it up for them and show them how to use it. And then they would have things like discussion groups, they would have information on their breast cancer, they'd have decision aids whether they should do a lumpectomy or a mastectomy, they could write their questions to an expert and get answers, so it was really a way to get information at your fingertips whenever you wanted it, whether that was two o'clock in the morning or, you know, ten o'clock at night.

Chris-

When my children left in the morning I was very alone and I could get on CHESS and chat. In the evening after I put them to bed at night I was very alone and very fearful and frightened of this disease and that changed for me when I could, would come onto CHESS and talk to women who were having the same fear as I was.

Usha-

When I got on CHESS I found a very very bright and very supportive group of women. They were both young and old, some were past their cancer journey, some were going through like I was going through, and the whole atmosphere was so open that I could talk about my anxieties that I could not even talk about, about them to my husband.

Fiona McTavish-

We've had, boy, hand, you know, a couple handfuls of clinical trials over the years with breast cancer women. We've been looking at the quality of life throughout that time of, "does giving it, people information support and decision making tools improve their quality of life?" And that's what we've found over and over and over again in our studies.

Dave Gustafson-

The second thing is that CHESS seems to have a big impact in relationship with physicians and just feeling like you, as the patient, are in control.

Fiona McTavish-

The other thing that we've looked at is how people are with their decisions, and if their satisfied with their decisions, you know, two months down the road, four months down the road, a year down the road. And that's the other place we've had an outcome, a positive outcome. You know, we've spent a lot of time studying this system. It's probably the most studied system, technology system, computer based system, out there without question. And we've done that, and we've been really good at that. We haven't been so good at disseminating it, quite honestly though, and so now we're really at a point where we're moving from clinical trials and learning about, you know, how people are using this system, to just getting it out there, and whether that is to hospitals all over, or to uninsured, however that may be, that's really what we're looking at. That's our next big step for us.

One of the things that amazes me about CHESS, and I've been working here for about 20 years and have had the privilege of working here, and what amazes me and makes me emotional about it, is the impact it's had on people's lives. And I can think of many many women who we've reached, some from the inner city, some from rural Wisconsin, from all over the place, and I think that the event that sums it up the most for me is that one year, after many of the women who have been on study for five years, and they are five years cancer free, they were still meeting, and they decided to go down to Disney World, and celebrate with one another because they've had five years of cancer free. And, to me, we never guessed that CHESS would have the impact that it did on people on these women.

Ellen-

Those of us who were still part of that group, we get together once a year still, we share so much of our journey, because most of us have been on that same journey for the last ten or more years.

Usha-

It's the kind of ongoing friendship, the ongoing relationship, and I think it is getting deeper and deeper. It doesn't matter if there are new people or same friends, and I think new people who join CHESS, they get this feeling that there are ties are old and people are there to support them.

Kathleen-

What I like about CHESS is we only have one thing in common, that's breast cancer. We never would have met each other under any circumstances, because we live all over, and we come from all walks of life and we don't have another thing in common, any of us, but we are just solid, strong sisters under the skin.