

CENTER FOR MIND-BODY MEDICINE
COMPREHENSIVE CANCER CARE 2001

CONCURRENT: Healing Communities

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P R O C E E D I N G S

MODERATOR: Joanna Bull, who is the founder and president for Gilda's Club Worldwide. She founded that 11 years ago. Gilda's Club is an international network of free, nonresidential cancer support clubhouses. The idea is to offer individually structured but flexible social and emotional support for people with cancer and those who love them, whatever the outcome, and from what we heard yesterday it also includes being able to work with caregivers in the health professions as well. Recognizing the limitations of institutional settings for healing, she's worked throughout her career to promote such things in noninstitutional settings, first for the Center for the Healing Arts and later for the Wellness Center, both in Los Angeles. Joanna has a master's degree in clinical psychology. So with no further ado I will turn over the program to David, who will tell us about the Bristol Cancer Help Centre.

DR. BEALES: Thanks very much. So I really want to say how much a pleasure it is to be here and the morning really sets the scene, I think, because it shows how much human needs need to be met in whatever setting we're living. And when people come into the Bristol Cancer Help Centre, which is now in its 20th year coming up to 21, we have seen such initial protest from medical establishment and now a place that is coming back into the light literally. But for me, coming to the Centre has been a journey of discovery through my own experience of living with cancer with my first wife's illness and subsequent death and her spiritual awakening and I think that picture really says it all. It's a William Blake picture and it for me is looking into the light and with one foot firmly on the ground, and our journey has very much to do with finding ourselves. And in the Centre we have a program for people with cancer and their supporters that is a retreat essentially so that people come into the Centre and they come from all over the United Kingdom and sometimes the world. And they come into a place of retreat and spiritual awakening, and that is absolutely fundamental to our whole approach. And what I'd like to do in this session is really introduce you to some of the concepts of Bristol but also to the practical approaches that we use so that when people leave us they can recreate in their lives some of the essential reconnections that they make with us. So we're a spiritual center but we're looking to reconnect people. And when people come into the Centre, and we are not truly integrated and this is something that may be still a dream for us, but we are stand-alone. We're not part of the National Health Service, although we're supported by the NHS to some degree. We have contacts, we have research contacts with those in the university, but we are a stand-alone. And all our finances come from our charitable foundation and wonderful people who raise money for us. This year we've had a quarter of a million pounds raised by women predominantly, some men who after the London marathon do a moonwalk. So at midnight they gather together, 9,000 this year, about 1,000 men, and they put on their bras and they at midnight walk the course with energy and fellowship and they're sponsored and this year the Centre and other charities have benefited and we've benefited from a quarter of a million pounds, which really raises our profile and the ability to work more fully. But people come to us and they come to us in a state where their options, they feel, have so diminished that they're boxed in. And we heard this morning from Dean Ornish and others how profoundly that affects, whether we call it depression, whether we call it hopelessness, how profoundly that affects our spirit and our ability to find meaning in life. So we see about 900 people a year coming through our programs. They're residential. They're at Grove House. We have wonderful support from people in high places. So Prince Charles is our patron and he continues to support us, sometimes getting a little obsessed with some aspects that we think are not necessarily so easy to follow. Why aren't

we doing more for the Gerson (?), with Gerson? Well, we're a small center and people come to us for retreat. What they find is a wonderful setting and I think the setting is so important. When they come through that door they are in an atmosphere where there is art, there is light, there are colors, there is welcome. And they step out of their lives initially for 48 hours in the introductory program and then, if they choose, they come back for a 5-day deepening retreat and in between there are educational events and courses and we run courses for massage therapists and complementary therapists and so on as well. So there's an education department. So the therapy program is centered around a residential retreat. We work actively with complementary therapists and self-help techniques. People experience not only the atmosphere of being together in a group, being able to express what they're feeling, having their stories heard, but they sample a range of complementary therapies and self-help techniques. And our aim is to create that safe space and a nurturing environment in which attention can be given to an individual's mind, body, emotions, and spiritual needs. So our core therapists and therapies are around transpersonal counseling. Clearly the psychosynthesis movement and other transpersonal counseling trainings give the therapists a sense of the divine and the spiritual in all of us. So those are our counselors. The group therapy, I can give you a little bit of an example. When people come in we see them. They are so closed down and our first session is to introduce us and then to give the space in small groups for people to tell their stories and to be heard. And I feel as a doctor I have to be really careful with myself, and this is another aspect of this work, that what I hear often makes me really saddened because people's experience of being heard, of actually being received in relation to what they choose to do, is often blocked by conventional doctors and part of our job is to help people construct a team, including doctors, on how to talk to your doctors about your needs and that is quite fundamental. Spiritual healing is very much part of the Centre and so healers are there and they are the group of people where in our feedback and in our evaluation there is the most joy and benefit that people have from those contacts. And those are both healing in groups but also individual healing sessions. Complementary therapy consists of body work, shiatsu, massage. Often when people come in extremely fatigued that sense of reconnection with their bodies through touch becomes the first essential to begin the process of getting people back into themselves and out of that box. And healthy eating is very central but perhaps less central than when we were first formed 20 years ago. But our approach is essentially a vegan diet but a vegan diet that is so imaginatively and wonderfully created by Jane Sen, who's written several books, including one that is really worth getting called *The Healing Foods Cookbook*. So linking to Dean Ornish's work, if people do commit themselves to the vegan diet they're eating organically, they're not eating dairy produce, but they have a plate that is filled with colorful and nutritious food, including moderate soy, and I think the soy controversy is around not having too much, and I think that's very much part of our program. So nutritionists are there. And we teach self-help and relaxation. We teach meditation and visualization. There are creative therapies, art, music, and dance, exercise, yoga, Tai Chi, Chi-Gong, and holistic nursing and residential nurses who are there for the people, particularly in the evening. So they choose. They may choose massage, they may choose reflexology. They're taught to massage each other if they wish and how families might reconnect with that. And then there are ongoing support groups. We reconnect people to support in their own areas so that when they leave they're able to create their own individualized plans. And why are we doing this? We're doing this because not only do we feel and know in our feedback, and we use an evaluation looking at how the primary concern changes over time and how the secondary concern changes over time, and Helen Cook (?) could describe that further if you wanted to look at that, but if we look at the left part of that screen I think it's suppressed anger impairs immune function. For me as a doctor in primary care where over 24 years I saw people overloaded and with increased arousal for me the stress is not so much stress as a word but it's whether you balance your ability to be in the world as an active person where we need stress and how you regulate your relaxation, how you balance your activity and your energy. And so alradian rhythms that we forget, I think, and I certainly can forget, are part of this reconnection with good living. And when people understand how to reconnect then they begin to live lives that are fulfilling. Insomnia and stress, when we're over-stressed and really over-aroused we over-breathe, in my experience. And that over-breathing often leads to early waking, the 2:00 to 3:00 in the morning waking, and many people are sleep-deprived. And so part of our evaluation with biofeedback now is to give people a sense of what happens when they're over-aroused so they can reconnect with their mind-body links. Drugs, I'll move from that but many people are taking a lot of drugs and actually many people are taking huge numbers of supplements. Many of them don't really make an awful lot of sense. So part of our task is to give people information to make good choices. So on the left immune suppression and on the right caring love. Hope, so fundamental, a

sense of living day by day and I think if people can get into meditation, perhaps very simply to begin with, that stillness and that shift from being in a busy mind to a stillness within, and it isn't terribly mysterious, meditation, although it is profoundly mysterious, and that's the paradox of really leading people into a space where they can create an experience for themselves. And we use guided imagery and it's been a great pleasure here to see how we could really make that more real for people. And leading to strong immunity and either living with cancer because 40 percent of our people have recurrences, some people making remarkable transformations over a long time living with cancer, and about 60 percent after the first diagnosis. So just to sum, the Tower of Pisa, positive experience, hope, spirituality, enjoying food but changing the way food comes into people's lives, and that has an implication for families, mindful eating. Flow, doing something that really gives you a sense of pleasure and real energy and that may mean for some people quite fundamentally changing what they do. We've heard of the wounded healer. And many men coming into the Centre come in very wounded and part of the journey is to find a new direction coming out of their woundedness and that becomes a focus in counseling. Imagery, teaching, self-disclosure, time, touch, and talk, altered state, mindful sleeping; and the effect of meditation to reconnect with quietness within. And the biofeedback I'll mention because it's something that's an interest to me that there are simple biofeedback techniques to do with mind-body connectiveness and how you really know what happens when your arousal, your adrenaline, levels go down. There are simple measures. All the measures that I really like now that the technology opens up for us, technology like heart rate variability, which is a very reasonable method of showing yourself how to reduce your arousal, your hyperadrenaline state, and create a state of balance within with some very quick, easy meditations, a heart-mindfulness meditation which works very, very quickly and people can see the effect actually on a screen. So Heart Meth (?) produced that and a company called Better Physiology do that. And similarly the mind-body link when we're over-aroused and over-breathing also for me has profound effects not only in my own experience but also in the research literature. And I'm sure that Dean Ornish's approach in his stress management reconnects people with breathing that is balanced breathing where they're not blowing off carbon dioxide and the effects that that produced, which is to constrict blood flow. Just two minutes of over-breathing reduces blood flow to the brain and also the coronary arteries by 40 percent. So these are major changes. So we're looking for some understanding of the systemic effect of too much for too long. So I put that up really just a little whimsical, a sense of the train as a journey, that people coming in are not just the people coming in because we ourselves as those who work in the Centre are really reminded constantly of our own journey and the need to actually look at our own lives and to lead our lives mindfully. And lots of things in there: Children, community, I'm not so sure about some of the smoke but, again, the train for me is a good symbol. I love a train that's actually chugging along and it seems to be more vital than the others. So how do we reframe some of these approaches? I mean, I'd like to hear your feedback really about what you think are human needs but I very briefly summarized what I think we're looking to reconnect people with and that's in the program. A need for attention, to be heard. There are gender differences. And then men are not necessarily good at listening. They need to often give comment. And the book like Men are From Mars, Women are From Venus shows that. I mean, it's a very simplistic message, but I think there are truths in that. So for the men and for the women a need to look at how attention is given. Real knowledge of the mind-body link becomes fundamental because if we don't understand that link we're not going to really be in tune with our bodies so that sense of reconnection with that. And about 30 percent or even more of people have lost that mind-body connectivity. They don't know how their body is signaling the need to be quiet. They are not aware or paying attention to the signals that the body has given that too much arousal, too much stimulation, is going on. We need purpose and goals. We need a sense the "we" and Gilda's Club and the sense that this giving back to the community is wonderful to have heard today. The connection is a connection to a spiritual. It's a spiritual connection. And that is a fundamental need, I think, for people that is often lost, a connection to something higher than ourselves, the mystery, really. Creativity and stimulation are, I think, fundamental and people are often in stuck states where they've lost that connection to art and music, and it's amazing just how opening that is. I mean, it's a right brain rather than the left brain but it's opening experience. Understanding, to be understood, and the sense of regaining control but also knowing that life can't be controlled, so it's living very much day by day. So coming back to Blake and that connection again with who we are but the transience of life, really. So to see a world in a grain of sand and a heaven in a wildflower, hold infinity in the palm of your hand and eternity in an hour, that is what we hopefully reconnect some people to. Thank you. (Applause)

MODERATOR: For those of us who just joined us, Joanna Bull will now talk about Gilda's Club, which she founded 11 years ago.

MS. BULL: Thank you very much. Those words from Blake are so inspirational. And your mention of your meditation and mindfulness puts me in mind of probably the Vipassana and other kinds of meditation that you're offering there. It's just so wonderful. This conference brings us, doesn't it, from the incredible vision, the global vision, of Michael Lerner and Jim Gordon and so on to seeing eternity in a wildflower and I think that that is the scope. I was very inspired by Jim saying that in the future we really need to integrate and incorporate a global view, a larger view, in what we're doing and not stay, not get caught, in a narrowly focused world. While David is doing that, I'll just tell you quickly that Gilda's Club was put together about 11 years ago, as Penny said. The notion of a freestanding cancer support community absolutely free of charge where people gather to help one another learn how to live with cancer whatever the outcome actually started in West Los Angeles in the late seventies and early eighties and started with something called the Center for the Healing Arts, which was put together by Dr. Hal Stone. And a critical thing happened when Hal Stone did that. Let's see what's happening. And that was that he did not set up his Center for the Healing Arts in a hospital or an institution. He chose not to have it in an institution or in a hospital or in a clinic but in fact he put together in a freestanding building such a gathering place. So this was really revolutionary. It set the course for what ended up as Gilda's Club these numbers of years later where we are noninstitutional and where we are not hospital-affiliated. We don't do anything medical. And now there are 13 Gilda's Clubs across North America. There's one in London that is struggling for funds. David has talked about how that can happen. But it's in hibernation; it will reopen. And we have 14 more in development around the world. Gilda's Club is now worldwide. And we say, "Living with cancer, come as you are," and we mean by that phrase to say that you are welcome. You are welcome whether you're newly diagnosed or whether you have been living with cancer for some time. You are welcome whether you're a person with cancer or a family member or a caring and loving friend. And I will just say about the development of this that I was running an early cancer support community, a version of The Wellness Community, which was founded by Harold Benjamin in Los Angeles, shortly after I was diagnosed with chronic lymphocytic leukemia. A patient was referred to me named Gilda Radner, who had just had her surgery for ovarian cancer. My oncologist was her chemotherapist and we were brought together so that I could work with her on meditation. I was at that time a student of Zen Buddhism and later became a student of Tibetan Buddhism and don't talk about that much, but it seems that you can talk about it in this room. And Gilda and I and Gene Wilder, her husband at that time, talked about how important it seemed to all of us that they have a place on the East Coast where they also lived and where others could come where this type of gathering place with the ideas that I had been gathering together could take place and after her death Gene and others invited me to come. And to just give you some idea of the kind of naivete that I brought with me they asked how much money I needed and I said oh, about \$10,000. Even 11 years ago \$10,000 didn't go too far but I borrowed a bit from some friends. I had a dinosaur computer. Somebody found an apartment for me and I started walking the streets and putting together materials and bringing this actually new concept to New York. And jaded New York, which had seen it all, really embraced it and I had the great good fortune of meeting the publisher at that time of People magazine who did a Publisher's Memo on it, and suddenly the country was embracing it. So Gilda's Club is worldwide now. And I'll tell you that we don't have, we don't present, we don't take any position on any theories of medicine, healing, stress reduction, psychoneuro-immunology, and so on although we're interested in doing some righteous research on the impact of Gilda's Club on the lives of the many people who use our very complex and rich program, which is very simple at base but has very many complex offerings. We leave that to others. And the kind of presentation that David gives on the immune system and others on the cortisol levels and all this kind of stuff interests us and intrigues us but what we're really saying is bring people together and create a community. Can you see this? This is about as lame as an A-V system ever gets, but I think you might be able to see it here. Bring people together in community and something wonderful will happen. You can call it healing if you'd like. You can call it loving if you'd like. You can call it caring if you'd like, caring about other people, getting outside of yourself, building bonds, camaraderie, mutual support, this happens, we know. And if the other medical things or psychosocial things or psychoneuroimmunological things happen let them happen, too. We don't try to make them happen. We give people choices so that they themselves construct their own program for social and emotional support. And they constructed, if you can see this, the community surrounded by something called the customized membership plan. And I'm just going to see if maybe I can focus.

There's a focus thing here. Thank you, Penny. Thank you very much because it's not working over here. Ah, suddenly light is shed. I like that comment today about you crack open. He's cracked, but through the crack the light shines. I love that. So we see a little light here. The customized membership plan is something that with the assistance of a trained facilitator, a new member, and, again, I want to say men, women, children, families, friends. Children don't create their customized membership plan but everyone is invited. With the help of a facilitator one looks very, very closely at what one's present and determined needs are. What kinds of things do you need to do to feel that you're socially and emotionally supported, that you're not suffering that sense of isolation and alienation and the condition myths that there's hopelessness there, all you're going to do is suffer and die? What are the kinds of things that you need that are really going to make a difference for you? And that customized membership plan is one of the things that I think really makes Gilda's Club quite different from other types of cancer support communities that I've seen or the wonderful support groups and all the stuff that's happening, that before you really go into the program you have a chance to look at and you look periodically at what you really need and you choose it and select it and do it yourself with other people. If you can see this at all this is a diagram of how the program basically is put together. What I'm going to tell you about in a little more detail is a feature that we've added to the program that you don't see here that's called PH&D, and I'll explain what that means. That's the program for "survivors." We're very sensitive to language at Gilda's Club, and I wish there were a better word than "survivor." I've had many people come up to me and say they don't like that. They don't like the battle feeling of it, the victim, the war, that kind of sense of it, but until somebody comes up with a better word, and I haven't been able to find it, this is for persons who have lived with cancer, perhaps living with it chronically, their family members who want to come to Gilda's Club and use this program plus some tailor-made pieces for themselves, including the giving back that David mentioned, which so many survivors talk about, and they use this and they themselves then enter into the community. By the way, I think that one of the reasons why Gilda's Club is as successful as it is is that we did not try to do too much. We had a mission and that was for people who were presently living with cancer and their family members and their friends within a year of diagnosis or so, flexibly so, and we put together a program that we thought would interest them with many, many, many choices and selections. We did not try to be there for cancer survivors who are many years past cancer in our early days. Now we feel stable enough, secure enough, the program has been shown to work enough that we've added that dimension. You can see that there's basic one, two, and three, and then there are three pluses down there and all of them in the context of community. Our hypothesis is, and it'll be interesting to see when we do our research how this bears out, that if people join together in these various activities that community will be built. There'll be mutual sharing, mutual learning, giving and receiving, and we talk about the kind of expertise that comes directly from living with cancer whether as a family member or a person who is in treatment. And we say to our clinicians who facilitate some of these activities that they're "untrained" because this is not a situation where people are given answers but where people are encouraged to find their own answers through exposure to different kinds of things that are out there for their social and emotional support. And the direction that they go in at the beginning might be quite different from the direction that they end up in as they go along. And I want to say about that customized membership plan that it's not too long. It's just long enough, like Goldilocks and the Three Bears. It's just long enough. But believe me, in the course of it, there's a lot identified, including what are your goals right now. What's working for you? What isn't? Who are the friends who would help if you would ask them to help out and in the basic three-plus Team Convene in fact those friends later on show up to assist or relieve the so-called caregiver by volunteering for all kinds of tasks. You can have 20, 30 people from your own personal social network, whether you're a family member who's overloaded or a person with cancer who's alone, and they can come in and volunteer to help out with the shopping, get you to chemotherapy, take care of the kids, give everybody a break, do all kinds of practical tasks and that really works. And it's so wonderful because you've heard so many people say just let me know if I can do anything and you never hear from them again. Team Convene takes care of that and Team Convene volunteers from one's personal social network are identified at the time of the customized membership plan. Basic I is support and networking groups. Men and women go into support groups together as adults. Family members go into support groups together as adults, all kinds of cancer together, and there are also support groups for teens and kids who are a bit younger, though in Noogieland, the children's program that you see down there as a plus, we don't call them support groups. We call it fun, play, and having a good time and we hope that parents are very engaged in the adult program while their kids are in Noogieland. Basic I also in addition to the support groups includes networking groups. That means

women with breast cancer can talk to women with breast cancer. There's often a didactic piece to it. Men with prostate cancer gather together, all kinds of things. We look at our population to see who's there and what kinds of things might be needed. A single parent, there might be a bunch of them at one time and they'll get together and network. So the impulse that most people have when they're diagnosed with cancer, to get together with someone who's going through precisely the same thing, is satisfied with the networking group. But we find that when people get together in the support groups, where ages, genders, cancers are all mixed up together the deeper human sharing and the looking at the deeper emotional aspects shared by all of humankind begin to be developed and exposed and worked on. So Basic I is both the support groups with mixed people and networking groups that are particular to what's happening in the life of the individual. Basic II, lectures and workshops. I'll be showing you some of the lectures and workshops that are being offered in the "survivor program," so I won't elaborate on that. But be sure that they're the kinds of things that David is talking about so wisely, the basics of nutrition, stress reduction, movement, being in your body, assertiveness training, spirituality, all kinds of things that people can learn about. Physicians come in and talk about latest breakthroughs in chemotherapy. Again, we're not selling anything at all. We're saying here's what's out there, folks. Take a look and see what you need. Put it all together for yourself. And Basic III are the social activities and they basically revolve around a potluck supper, though they can take many other shapes. We've had in New York students from the Juilliard School come and entertain. People bring supper dishes and have a wonderful time. We have joke fests where traditionally at Gilda's Club if you tell the best joke you go home with a rubber chicken. I mean, at times we're silly. Gilda's Club started with the notion, as Gilda had said, that having cancer gave her membership in an elite club she'd rather not belong to. So we start with a little bit of a chuckle and I assure you there is as much room for tears as for laughter, for joy as for exploring and working with pain. The whole gamut of the human experience of cancer, living with cancer whatever the outcome, is explored at Gilda's Club. I think I've talked about the pluses. You've heard about Basic I, II, and III, the Team Convene, Noogieland for children. Family Focus is another part of the plus, and there we bring the entire family together to see how they can work as a team, see what the family rules are, what's working, what isn't, and we send them home with some homework. We try, again, not to make it a therapeutic in the obvious sense experience but a team-building, family-building experience, and that is however it is that you define yourself as family. And I may not have much time to go into PH&D today but I want you to think of this program, if you will, when you're looking as I go quickly through the remainder of what we're talking about here. By the way, we're also going to be taking Gilda's Club online for people how are very, very, very far from these clubhouses. And we have a wonderful grant and some people in the corporate world who are helping us with it and I think it's really going to make a difference. We found through months and months of exhaustive research and work on it that actually this program very well transfers to the online world. Here's PH&D. This is a continuation program for the survivor and, again, I say it includes others who have not been members of the program or who have perhaps been in the program, recycled themselves as volunteers after their survival, trained by us to continue to help perpetuate the community but may want to return to go into exploring some of the deeper issues that Michael Lerner was talking about that we have the option to look at in this world. Well, certainly having cancer gives you a different perspective. Living with it gives you a different kind of perspective. And I wanted to show you here what a typical clubhouse looks like, just so you see what the ambience is of it, the kind of feeling that there is, and, believe it or not, we're actually trying to reproduce this online. I call it everything but the hugs and more and the more is what the Internet gives you these days in terms of information sharing, lectures, and learning opportunities as well as community building. You can see this is not a typical place. This is actually the entry place to Gilda's Club. And what you saw was not an intake situation but a welcoming desk. Here it is, a welcoming round table. Everything is cozy. This is our kitchen. Here's a living room. And that kitchen leads into this great big room. I love that mural. We don't have any windows in it so we put in a wonderful big mural of a sky and openness, that Blakeian feeling of all kinds of possibilities, and this is where we have a good time, have our lectures and our workshops and our parties and things. Here's the family room. People gather around the kitchen table. This is the it's-always-something room if you want to just get away from it all and a typical group room or a networking group room. Here's a children's room, Noogieland, lots of fun, and that's the ambience. That's what Gilda's Club looks like. I want to just take a second, even if I am not able to tell you much more about our PH&D program than this, to tell you what it stands for and maybe leave the rest up to questions because I told myself I would stick to the timetable here and stop at noon. I want to tell you, first of all, I did mention that we have fun with the idea of the person with cancer, living with cancer, as an expert. And that really is true that there is

so much inner wisdom that we have that we don't begin to draw on that we don't begin to realize is there whether we're a person with cancer or the family member who's impacted, the next-door neighbor who's really involved, and our feeling is that that wisdom is not only individual, it's collective, and that with a community experience like the one at Gilda's Club, it just grows exponentially. And I think survivors who are a way out from it all actually have their own resources that are developing. They may be still feeling some challenges that haven't been resolved. And here's why we called it PH&D. Obviously looking at expertise, it's a play on Ph.D., graduate work, in living with cancer. Perspective, as cancer survivor people often experience a vastly expanded perspective on self, other, and the shared world of cancer experience, a perspective that offers richly varied opportunities for emotional, social, and spiritual deepening and meaning. And I notice that people are talking about meaning more than they used to talk about it and I'm just delighted about that. Helping hands, time and again "survivors" report their impulses to give back in gratitude for their continuing daily lives. Often this wish to extend their wisdom to others is focused on giving to those newly diagnosed, in treatment, or on their families and caring friends who are inhabiting the same territory that the survivor knows so well. Finally discovery, a commitment to exploring the deepened perspective on living and dying that experiencing cancer can offer leads to a search for the discovery of opportunities for learning, growth, definition of relationships, closure, and meaning with respect to self, others, and our shared experience. So it seems pretty silly, PH&D, but actually we're trying to get at something that has some depth and meaning. And when people come together and they're now beginning this program we're seeing already that that's exactly what happens. I'll tell you quickly that, again, they're using the same program and the children themselves who have been Noogieland attendees and members will join, that is to say children who may years later want to come back or children who are very young might want to come after the death of their parent and extend their stay in Noogieland even though they may not have been members previously. And this is interesting to bring people who are newly diagnosed and long-term survivors together to tell their stories as an orientation to Gilda's Club. I think that this is a bold act here and we'll see what happens because it should be a very interesting mix. I think already by bringing them together people are going to kind of get out of that sense of there's nothing here but me, myself, and I, and maybe there are other people and I can get some hope and inspiration from people who are way down the road. These are the kinds of groups that I've mentioned and these are the networking groups. You all know what these are. I don't need to go into these at length, but these are the kinds of networking groups that will be offered and are being offered now. And there are lectures pertinent to persons who are survivors. You can imagine that for those who are presently living with cancer there are different kinds of things but some of them are shared. These are things that people sometimes after years of living with cancer may still want to revisit. Cancer and spiritual faith, I'm just so happy that it's okay to talk about that. It's okay to talk about death and dying these days. These are things that even 11 years ago you had to be real careful about because of the political climate around what was acceptable and what wasn't in terms of putting together a cancer support program. Social activities are terribly important and a lot of these are for people who are years out in their survivorship. And here are things that people can do together that continue to build community and make it enlarge. And I just want to say that giving back, I think, is just going to be such an important part of our program and I want to tell you that these are the things that I think that David particularly because of how his program is set up would appreciate, going inward to deepen the insights, looking for meaning, and using what you're learning to deepen your own personal experience and that of others. And I'm hoping very much that this will be an opportunity. Sometimes with cancer although it's years past many old wounds still exist. And people can come back and explore them in a fresh kind of way. And I like that last phrase, members use one another's expertise as a resource, and that's how Gilda's Club works. So I thank you very much for listening to me. I actually stayed within a couple of minutes, went home last night and took half of the slides out so you had a kinder, gentler lecture today than those who came yesterday. I was so excited about this program I had everything on there. I think you got the idea. Thank you.

MODERATOR: Two questions for you, Joanna, before I turn on the lights. One is what cities are you in and, second, what are the categories of information you wish you could have given that you didn't in case someone has a question in those areas?

MS. BULL: Oh, thanks, no, it was just that I wanted to say more about the kinds of activities because there are so many things that you can offer. The sky's the limit. Just use your imagination. I would say

that in the different cities where there are Gilda's Clubs, for instance, in South Florida, there's more of an emphasis on overt spirituality than there is in New York where right now with the greatest spiritual challenge that perhaps we've ever faced as Americans we're all toughing it out. Gilda's Clubs are in 13 different cities and I did have some current Gildagrams. If you're interested in being on our mailing list just please sign up on the back of this paper here and I can send you a Gildagram. It started out in New York, went to Florida. There is a cluster of Gilda's Clubs around the New York City area, a cluster in upstate New York, Buffalo, Rochester. These are either in development or open. The Chicago-Midwest has a lot from Quad Cities to Chicago, Milwaukee, again some in development, some open, out to Seattle, Dallas, Texas. It just doesn't stop. How about Maison Gilda in Montreal? And the little thing that I'm wearing today because my regular Gilda's Club pin popped off yesterday is actually Gilda's Club Greater Toronto, where prior to coming here I went and helped cut the ribbon. And at the very firehouse in downtown Toronto where Gilda Radner, our wonderful, beloved comedian, had her first career opportunity. And the place where her stage was is where the big community room is in the Toronto Gilda's Club. So thank you, Penny. QUESTION: Is this a drop-in program or residential or a combination of both? MS. BULL: I'm sorry. It's nonresidential. This is why I said at the beginning that Hal Stone made a really seminal decision there when he didn't put it in a hospital setting, didn't associate with an institution or a clinic, decided that it would be in a freestanding place. And what happened was that when people came together in this freestanding place and shared in the support groups that the lectures and workshops were the most natural thing to add and suddenly they were knowing one another and it was a party. So the pieces of it fell together, nonmedical, nonresidential, nonagency, not social services, but a gathering place where people put together their plans, share them, and learn together.

MODERATOR: David, would you say about the residential and how long? It wasn't clear to me yesterday how long people stay for the initial and all of that.

DR. BEALES: Well, they come in the night before for the initial residential and then they stay for that night and the following night. So they start the program the day after they've stayed overnight and got familiar with the rooms and the setup and so on. So they actually stay two nights initially on the introductory course and then they may choose and quite a number do to come back for a deepening five-day program, which follows for most people relatively quickly from that initial 48-hour introduction. Because we're a flexible cost people pay if they can afford it but if they can't afford it they're always provided with financial support. And the cost for a 48-hour residential with dollars as they are is probably about \$800. For a full year, including the 48-hours and the 5 days and day follow-ups, it's 1,000 pounds, so it's about 1,500, isn't it, \$1,500?

QUESTION: I have a question for you, David, if I may. Would you say that your program is rather like Michael Lerner's Commonwealth in the sense that there's an intensive residential experience?

DR. BEALES: Well, I mean, certainly Commonwealth came to look at Bristol and spent time with us and I think there is a real value in having a retreat setting for some people, not for everybody, but when you're really needing to get outside the pressures of your life it becomes essential to have a safe space to do that and enough time. That's one of the issues, I mean, how to spend time when you're coming into a program and are exhausted. And so we're looking at preparing and people are always prepared coming in. They get a video, they get information, they get understanding, we hope, of the mind-body link and what the programs are about, so we do precede it. But I think that coming into a program when you're really able to have a little bit more energy because you've started a nutritional program, you've started some supplements that we recommend, and so on is often more helpful, I think. So that's some of the new development that we're working on.

MODERATOR: Other questions from the audience?

QUESTION: This is for you, Dr. Beales. About how many support people, how many employees if you call them that, do you have? What's your average attendance over a year, just the nuts and bolts of doing it?

DR. BEALES: Well, over a year 900 people, about, come into the programs and the support staff, Helen would be better at this because she's the therapy director and the nuts and bolts of this but she manages about 45 staff. But this is slightly deceptive because the therapy staff on the whole part-time, they have their own private practices. They come into the Centre and the Centre provides support and what is a very important part of this process. This is supervision so that people who are working in this area are given paid time to process their own issues that come up in the therapy group. So that's an important part. But we have a chief executive. We have a fund-raising group of people. We have an educational department and we're increasingly outreaching, so we provide support groups and a general practitioner, surgeries. We run support groups for families and also for people with cancer. And in corporation with the University of Exeter we validate qualifications for massage therapists. We're part of an MSC course for people training in complementary medicine. So we've outreached but we are independent. We do require independent funding. So we also have a shop and so on, yes.

MODERATOR: Other questions? Yes. If it's an easy one I'll paraphrase it but if it's complicated I'd rather you do it here.

QUESTION: I think mind-body therapies are extremely useful. There's no question about it. And the empirical data and the scientific data back that up and anecdotal evidence. What I find difficult is integrating that into my daily schedule. And I don't have cancer, I have fibromyalgia, but it's just as important to integrate those therapies, and the more you practice them the more of a benefit you get from them. So my simple question is are there any portable biofeedback machines that someone could use at home because -- or do they exist and how would one get one?

DR. BEALES: Yes, I mean, they range from very simple, perhaps your comment, but we heard of things to do with temperature, much slower responses in my experience in biofeedback, but when your arousal goes down you can show changes in your body temperature and that's an easy thing to show and they're quite inexpensive. You can have the galvanic skin responses, which again respond to arousal, but they're not very sensitive. And what I really think exciting are the two ways that give people information about their internal body states. And that's heart rate variability, where there's very good research evidence that your autonomic system when it's really aroused is shown on a measure that then comes onto your screen and you can then do something very practical to give yourself an ability to shift arousal, to get into states of calm, and with some very nice interactive games. So one of those is Heart Math. It's about \$250, I think, but you get interactive games. And some of the research shows that children using this in their lives, because children increasingly pressured connect with that mind-body link and they know what creates the best internal state for learning because if we're over-aroused we shut down our brains. And the next link is breathing. If we're over-aroused and we're over-breathing then that has the same effect. So Better Physiology has a device that shows you on a screen what your carbon dioxide in the out-breath is, and that's interactive combined with heart rate variability. And the cost of that has come right down, so it's about \$800, I think. And I think there is a new field opening up where I hope and I do believe that people can really begin to understand how their bodies work and to do something actively about that. And I think this is very exciting because it's really taking control of your own body and actually understanding what creates well-being because if we're over-aroused we're in a over-burn metabolism called catabolic metabolism. If we're self-regulating we're in a state of anabolic, self-regulating homeostatic. If we're over-burn we change a whole range of fundamental physiological changes. We push out bicarbonates in our urine. We change the buffers in our internal systems. We change the ratios of calcium and magnesium and in fibromyalgia that's actually very important because it means the muscles are much more sensitive. We can't respond to exercise in the same way because we can't buffer the products of exercise, lactic acid. We don't have that in our body so fatigue takes over. So there are some very fundamental things that I think people can get from relatively simple biofeedback mechanisms that will get cheaper as people discover them. So I could give you some details if you want.

MS. BULL: Let me just make a comment on that. I just wanted to add to that that the most inexpensive portable machine is yourself. And that's not to in any way suggest that the types of things that explore the nuances and in-depth responses are not terribly important but it is also true, and we do this at Gilda's Club, that learning to actually read yourself, to really understand what these many ways through your

behavior is to control, how you're experiencing mind-body beingness, that those things can actually break down to some very simple things like learning how you can direct heat to your fingertips. And when that happens you begin to get a sense, gosh, I've got some control here and you take a little more seriously the meditation that maybe you wanted to skip because you wanted to go shopping on your lunch hour, this kind of thing. So it's portable and it's cheap and it can lead you in the right direction.

QUESTION: I have a question that relates kind of both of you for different reasons and also to what we've been talking about and that question has to do with how do you deal with the issue of anger management or -- that's not the right word, with the issue of anger and the suppression of anger that you referred to earlier contributing to the etiology of illness and bringing people to a place of peace and serenity without somehow communicating to them that experiencing anger is not okay? So I'd like to hear from both of you.

DR. BEALES: Well, very quickly, I think that firstly there's a need to really create a space where it's acceptable to express what is held in. And that is possible for some people in the right counseling and sometimes in groups. And we've heard how the setup of David Spiegel's groups allows that. It's essential to follow the affect and that's where a skilled leader, I think, is really important, that somebody who's trained in group dynamics can facilitate that. And it is so important. I mean, I fundamentally agree that if you look at the literature somebody who holds in their feelings in relation to coronary artery disease has a relative risk that's akin to smoking, so this is a major added risk for people. So it's creating the space to allow and then to give people permission and then, because these feelings are new, to really allow people to see the importance and some practical techniques. I mean, Jim Gordon mentioned that if you're really fed up in his group and you know where you are you take a pillow and you really get out the emotional expressivity that is in your feelings, but you don't take it out on your spouse or your husband or whoever.

MS. BULL: I would say that at Gilda's Club it's in the support group basically where trained, certified, licensed psychotherapists, whether they're psychologists, family counselors, psychiatrists, whoever, who are staff members and who are trained by us and supervised by us as contract people work in the modality basically that David Spiegel talks about. We add one dimension and that is that the therapist or clinician, whom we call a facilitator, is trained to actually be an authentic human being himself or herself in that group and to actually freely disclose, to share what it is that he or she may actually be feeling, to use oneself as an instrument with one's own awareness of what's going on as an authentic way to respond to what the others in the group may be showing to unearth that emotion, to pick up on it, to explore it, to take it to a deeper place. But it's really a challenge because in doing that the group members are invited to themselves pick up on that so that there's a training process going on where people not only are themselves as facilitators aware of what they're feeling but they're modeling for others to become aware of what they're feeling so that they in turn can be there for one another to be sensitive to one another's emotions so that when one is feeling some grief somebody just doesn't pop in and start changing the subject but in fact the group is trained through this to be aware of those supportive feelings. As far as anger specifically is concerned I think you need to be real careful in group situations that it doesn't become a place for dumping and abuse and things like this. So we look carefully to see whether people are in a situation where their distress level is such that they may need some serious counseling and referral out because we're not set up in any way to handle stuff like that. And I also am of the school, I must say, that believes that banging pillows with batakas is a product of the sixties that probably should stay there, that in fact it doesn't really transform anger, and what we're looking at in the ideal world to me is working with emotions, to actually transmute them. And in order to do that we need to have a whole plate of activities, including meditation, including awareness meditation, including giving back, including learning how to be in the world on many, many, many levels that actually transmute anger into some other kinds of emotions that are more workable and serviceable in the world.

MODERATOR: Other questions? Elizabeth. How does one start Gilda's Club?

MS. BULL: Basically what we do is ask you to get in touch with Gilda's Club Worldwide. I have my card there. If you could first go on the Web there actually is a whole lot of information on how to start Gilda's Club. It's www.gildasclub.org on my card, and you'll see there what's involved. Basically movers and shakers in a particular community who want to see it happen, who know people, who believe in it, who

have the passion for it, go out into their community to check out whether it looks like there's some interest. They do a demographic study. We make sure that it's something that's needed and that it's an area that can support it. We ask for a business plan. We ask you to visit us. We have extensive training. We hope that people will not only have a business plan that includes some serious fund-raising but they also will have the capacity to sustain it in their communities. So it's quite a complex process. We first give a letter of agreement. Later on when we open I handed over the charter in Toronto. Toronto took the longest that any Gilda's Club has taken, six years in that community to raise the dollars to get the building. Remember, you have to have a building. You can rent it but you have to furnish it and you need trained staff, though there are many volunteer aspects of it that make it quite cost-effective, like the members themselves who graduate into being volunteers and facilitating the new member meeting. All of the lectures and workshops are given free of charge and you'll find that there are people in the community who are just so eager to do that. We don't pay anyone for that and what's great about bringing in different people who do different things is that people line up to show what they do and the member doesn't get attached to one particular way, can actually learn more and then really have an opportunity to select what is best for himself or herself. So there are ways that it's cost-effective, but it also, as Michael Lerner says, free is expensive. But it takes passionate people in the community who are willing to hang in there. The record has been a couple years to get it all together.

MODERATOR: Anyone else? Yes. The question was what are the esthetics of the Bristol Cancer Help Centre?

DR. BEALES: Well, I think the esthetics are that people are coming into a house that has a real spiritual energy. I mean, the actual house was a convent, and so the spirit of that place and the devotional aspects I think resonate within the building. So they come in and the floor is blue. There are lights, gradations of blue and mauve in the main room. There are pictures on the wall that are original, that are about nature on the whole but also spiritual paintings we see in Blake's paintings. In the rooms there are comfortable chairs but it's not a cluttered space. The main space is really quite an open space. There's a central candle. Obviously there are the support things around, water and music and so on, but they're quite discreet. And the therapy rooms are painted by the staff. They give their time to do that and there's a sense of trying to create an atmosphere that is healing. And we get given works of art and that's a problem sometimes because people are attached to their own particular work of art. And so how do you say no? And that sometimes is a real issue when you have to do that. You have to do that subtly. And it's subjective, isn't it? And so there's a little committee that does that. And the founder's presence is very great, I mean, Pat Pilkington, original founder, Penny Bron (?), who lived, not survived, but lived extraordinarily well with recurrent breast cancer over 14, 15 years, and managing that for herself until she died three or four years ago. But that sense of the passion is fundamental I think, people with passion, and Pat Pilkington, the original founder, has passion as has Joanna. And the people who come into centers need the passion and the commitment to bring about a vision that perhaps others would not think is realizable. But there's a wonderful quotation around commitment that when you're committed the world draws in aid. So it's that sense of giving back and for me coming into that I or we, so it's really dropping ego and really opening up commitment and service. And I think that sense of giving service becomes a fundamental part of the program.

MODERATOR: Other questions? I had one last. Is the heart mindfulness meditation something you could leave us with?

DR. BEALES: Yes, I could. Do you want to just become comfortable? And just a sense of being comfortable in the place that you are and just feeling your body resting on the chair and just allowing your breathing to become part of you so you become mindful of your breathing and you allow the breath to enter and leave in its own way. So as you breathe in you're breathing in energy and renewal and life and the spiritual connection. And as you breathe out you're letting go of what you don't need here. So as you breathe turning your mind inwards gently, moving your attention to a place where you feel so loved and so received. That may be a place at home or away and into that place you may choose to bring your loved ones or you may be there alone but a sense of love and appreciation for being there and for being you. And move that sense into your heart, really feel that sensorial place in your heart, and bring those

feelings of love and appreciation and centering and breathe in that love and appreciation of yourself, the work you do, love and life, and enjoy that feeling of renewal and connection to our higher self, holding that, taking it with you into whatever branches of life for you are next and then when you're ready coming back into the room, just centering yourself here again.

MODERATOR: Thank you very much, David, and shall we say a thank you to Joanna and David for their presentations? (Applause)

MODERATOR: Thank you all for attending this conference and for attending this session.

(Whereupon, the PROCEEDINGS were continued.) * * * * *