Mr. Kuhn began with some preliminary remarks:

Today is a landmark day in the history of this conference and the history of this organization. This is the first time that people with Alzheimer’s disease have been part of this event. It has been a long time coming. Others with the disease will be regularly featured at this education conference in the future. If you have not done so already, I challenge you today to make sure that people with Alzheimer’s disease are incorporated into your own educational events in the future, whether it is a conference, a seminar, or an in-service program. I also challenge you to involve people with Alzheimer’s disease in your research projects, advocacy efforts, fundraising events, and the work of your committees and boards.

People with Alzheimer’s disease have an important contribution to make and many of them are willing and able to offer their time and talent. They simply need to be invited and directed how they can be of help in a cause directly affecting them. We need their voices to sing in the choir. All of us can listen and learn from them. They have much to teach us about how to face adversity with courage.

The theme of this year’s conference is “bridging research and practice.” As a result, 2 people from the past are on my mind today. First, Dr. Alois Alzheimer represents the research side (slide photo of Dr. Alzheimer appears). When in 1906 he first described the case of a middle aged woman with a peculiar disease of the brain, he set in motion the hunt into the causes, treatment, and prevention of the disease that later bore his name. For nearly 100 years, particularly the last 20 years, scientists have been looking for answers to its mysteries. Billions of dollars have been spent on this research, and amazing progress has been made. But it has not been enough to satisfy the needs of the millions of people now living with Alzheimer’s disease every day. If the United States can find half a billion dollars a week to help the people of Iraq to rebuild their country, we can find the money necessary to bring real hope to people with Alzheimer’s disease and their families. Let’s make it a priority in our national and state politics. We need many more voices in the choir to make sure that our elected government leaders hear about our important cause.

In the meantime, what can we do for people with Alzheimer’s disease? This question leads me to a second person—Auguste Dieter, the woman who Dr. Alzheimer first described in 1906 as having symptoms of a brain disease (slide photo of Auguste Dieter appears).
In 1902, she came to live in the hospital in Frankfurt, Germany, where Dr Alzheimer was working at the time. In this photo, she is 52 years of age and she died just 2 ½ years later from complications of advanced dementia. She looks worn out and utterly alone. Can you imagine what her final years must have been like in a hospital 100 years ago? Sadly, for some people today, conditions have not changed much since that time.

Dr Alzheimer’s written notes about Auguste Dieter’s case reveal nothing about her care or quality of life. He simply charted the 3 Ds that dominate modern medicine still today—disease, disability, and death. She was a woman clearly dying from a disease, not living with it. She was a victim of what the late Tom Kitwood referred to as “a malignant social psychology.” Her potential for living with her symptoms was never realized. People in her life failed to understand what she was experiencing and what she needed to cope successfully with her confusing world. They did not appreciate her need for intimacy, community, and meaningful activity. They did not believe that their own attitudes and behaviors needed to change to suit her needs.

It is our responsibility to create the conditions necessary for millions of others like Auguste Dieter to maintain their dignity and live life to the fullest. This takes human ingenuity, skill, and compassion. It also takes money for services currently not funded or underfunded. It’s a huge and daunting task before us now and it will grow more pressing in the years ahead. It will take an entire village, indeed a 100,000 villages.

We need to recall the pioneering research effort of Dr Alzheimer for inspiration to work toward a world without Alzheimer’s disease. Scientists today deserve the recognition and funding necessary for this painstaking effort. At the same time, we must remember Auguste Dieter, who represents millions of people today who are at risk for poor care in our homes, our programs, and our care centers. They cannot wait for scientists and the pharmaceutical firms to come to their rescue with a magic bullet. They do not want to spend their remaining days caught up in disease, disability, and death. They do not wish to be poster children begging for our sympathy. They want our respect. They want to thrive, not just survive. They want our help to enable them to focus on living with Alzheimer’s. Caring families and caring professionals deserve recognition and funding for this effort.

I wish to end my opening remarks today with 2 modest proposals. First, let every new dollar devoted to research be matched for care and services to people with Alzheimer’s disease; especially their families who are their main helpers. Second, let the current generation of Auguste Dieters be given a prominent place in the choir. Let their voices sing out loud and sing out strong. Not in spite of their symptoms but because of their symptoms, these friends of Auguste can teach us all how to sing better and live more fully.

Now it’s my honor and pleasure to introduce some friends of Auguste. These are people living with Alzheimer’s disease—three of them with the disease joined by their family members. I am so grateful and humbled by their presence here today.

Voyer Howell, 71, was diagnosed with Alzheimer’s disease in 2001. A native of New York, he worked a variety of jobs throughout his life and finally was a tour guide in Chicago before retiring at age 65. He and his wife, Kathleen Hotton, 64, have been together since 1978, and they live on Chicago’s near Southside. Voyer has two children by a prior marriage. He is a regular member of a support group for persons with memory loss at Northwestern Memorial Medical Center in Chicago. He and Kathleen are still world travelers and share a great love of opera. Kathleen joins him on the panel today (Figure 1).

Joan Cahill, 75, is a retired registered nurse who was diagnosed with Alzheimer’s disease in 2001. A native of Chicago, she lives on the city’s Southside in close proximity to family and friends. She has been widowed since 1982. She has seven children, fourteen grandchildren, and three great-grandchildren. All of her four sons and three daughters live in the Chicago area. She currently volunteers one morning a week at a local hospital and is a regular member of a support group for persons with memory loss at Northwestern Memorial Medical Center in Chicago. One of her sons, Terry Cahill, joins her on the panel today (Figure 1).
Marty Bahr, 54, was diagnosed with Alzheimer’s disease in 2000. He and his wife, Laurie Bahr, 46, were married that same year. They have lived in Bartlett, a northwest suburb of Chicago, since moving here from Seattle in 2002 when Laurie received a job transfer. Marty’s two children by a prior marriage, three siblings, and parents live out of state. He was an executive in the insurance industry before Alzheimer’s disease cut short his career. At present, Marty is working with the Rush Alzheimer’s Disease Center in Chicago to form a support group for persons with early-onset Alzheimer’s disease. Laurie joins him on the panel.

Daniel Kuhn: As I thought about the opening question for this morning, I thought I’d begin with you, Joan, as you are pretty typical of people with Alzheimer’s disease in that symptoms were very slowly emerging and there was a great deal of confusion early on. Please share with us what series of events led you to believe that maybe you had some memory problems.

Joan Cahill: I really am not able to slice them out in tiny little packages. In fact, my answer usually is, “I don’t remember.” It covers a blanket number of things. I’ve never been good at directions, but I became really bad at directions. I found myself in a store that I had shopped at fairly frequently and they had redone their displays, so things were not in the order I remembered them. Largely, it’s quite true that at this point that I don’t recall a lot of the very initial situations that I found myself in. I don’t know if Terry could fill you in any better.

Daniel Kuhn: If I recall correctly, you experienced the death of a brother and sister during this time and there was some thought that maybe you were depressed quite naturally over the loss of your brother and sister.

Joan Cahill: Yes, it’s true, I had a sister who died after a long illness and then I had surgery. Then, not long after that my brother died in a fire in his home. This all happened within a fairly short period of time, so surely that was a figure.

Daniel Kuhn: So as a result, you were initially treated for what was thought to be depression.

Joan Cahill: Yes.

Daniel Kuhn: And your symptoms alleviated a bit although the memory problems persisted. Terry, please share some of the things you and other members of the family were witnessing at the time with your mom.

Terry Cahill: Sure. At the time, we were actually hoping it was depression. Certainly there was a lot of depression based on the events, but there was just a heightened anxiety and confusion around paperwork, bills, scheduling, getting lost. Another time my mom got lost on a route to an aunt’s house; a route she had taken many times and so there was some concern about that. We were also beginning to notice more and more repeating and having trouble finding the right words in the middle of a sentence, that sort of thing. Also, my mom has a very broad range of vocabulary, but was having a difficult time.

Daniel Kuhn: Okay. Now I’d like to turn to Voyer and Kathleen (Figure 2) because I think you also had a typical period of confusion and uncertainty. Voyer, can you recount an instance when you first realized that your memory and thinking were not what they used to be?

Voyer Howell: Yes, there were certain events that took place that I had excuses for like I’m overwrought or over-tired. But one day I had a group of seven children whose families entrusted them to me and I took them out to a park and we rode horseback riding. Well, one of the horses broke away from one of the children. I chased after it with my horse like a cowboy and jumped on its back and yelled, “Whoa!” and pulled it back. So, I was a hero, right? Well, actually I was shaking like a leaf. But, I made it and the kids were unharmed. That was just one event, but the same day, when I brought the kids home, I felt a little disoriented, but just thought to myself, “Well, the kids just wore you out, you’re just overtired.” I didn’t call it disoriented then, but I know it now.

During that time I was a tour guide. I drove a huge bus and took people to places they wanted to see. One day I got disoriented and took the wrong course. The next episode would be when my wife and I were driving. On a trip home one day I drove out of the lane and into where there were gravel pits and across the traffic. My wife said, “Honey, you’re going off the road…” And I said, “You’re just overwrought. I’ve been driving for years and I know what I’m doing!” The way I saw it, I just didn’t want my wife to tell me how to drive.
Then, two days later, I was in another situation and the same thing happened. I got lost. I’m not a person who gives in easily. It’s not like ego. Well, it is pride that is ingrained in me. I was a member of the Red Cross and I was out on a call to rescue some people in a fire and I got lost. I asked myself, “What’s the matter with me? I know these streets.” I did write down the destination on a sheet of paper, but couldn’t find it. Well, I kept going and eventually, I hit a tree. Actually, drove up a tree. I was dumbfounded and wondered how this could happen. So, I called my wife and told her I was having a bit of a problem (laughter). I was kind of shy about it. She said, “What’s the matter?” and I told her not to be alarmed, but that I had an accident and was lost. Eventually, I got back on the road and was still lost so I stopped at a restaurant and called my wife again and she came to where I was and led me back. Then…

Daniel Kuhn: This story gets more colorful every time I hear it. (laughter)

Voyer Howell: Okay, I’m winding it down. So, anyway, I was lost three times and I was so stubborn, I just looked over it. But, something was wrong. My wife was beginning to notice a problem, too. She made a doctor’s appointment and I went through a series of tests.

Daniel Kuhn: I’d like to ask other panel members about the testing which, in most cases, was pretty painstaking. Kathleen, can you share what you observed with Voyer in addition to these instances that he explained to us?

Kathleen Hotton: I really spent a lot of time holding on tightly to the handle above my seat in the car because it was a really frightening thing. And, of course he would just say, “You’re overreacting.” This was really quite bad. You have to understand, though, the encounter he just explained to you, he started out on this call for the American Red Cross just a little before midnight and was gone until six in the morning. I was beside myself. By the time he called me back, I had the police at the door. The other thing I noticed probably even before the driving went bad was his ability to see things the way they really are. He could see well, but he could not process well. The very first thing that I think I noticed was his inability to tell time. He had another very bad accident as well. So, I don’t overreact anymore (Figure 3).

Voyer Howell: And I don’t drive anymore! (laughter)

Daniel Kuhn: I’d like to ask you, Marty, about what led up to actually seeking out a diagnosis or a medical evaluation.

Laurie Bahr: (after Marty shows confusion over the question) Regrettably, I don’t think Marty had significant or earth-shattering events such as with Voyer. It just seemed to be a series of more subtle things such as problems with the computer at work. What I can recall is from time to time he would come home from work and tell me of the problems he was having with the computer. Frequently I would tell him something and he would deny that I had told him—it was a lot of events like this. We never suspected it was any kind of cognitive memory issue going on until we went into the doctor. Somehow he suspected that Marty might have Alzheimer’s and put him in for the memory test. That’s where they began to suspect that there’s some kind of cognitive dementia going on. There were no driving incidents yet or nothing really obvious, but I think Marty was in such a high-performing profession where the expectation was so high, that it was more noticeable.

Marty Bahr: When we went to Dr ___ and when he decided that I had this problem and I asked him what we could do about it and he said, “I don’t know.” Well, talk about feeling like someone put a knife in your gut. But from then on we started to meet with the right people and weeded out the people that really didn’t know what to do. The real problem was that they didn’t really know what to do with me. I’m sure some other people have had the same experience. Doctors today don’t have a clue, as far as I’m concerned, what is going on in our minds. They don’t understand how distressing it is to not be able to remember things, to feel embarrassed at times. But, I’ve gotten over that. I ask questions. And I’ve been very fortunate with the people in Chicago. The doctors and nurses have been phenomenal.

We need more time with our doctors. You go into the office and we are hurried right along and do not get the answers we need. There have been times when I’ve gone into
Joan Cahill: Yes, I disliked it. (laughter) When we start-
ing off on this little journey the testing I had done initially
and pretty much it’s the same testing one does. I hate draw-
ing those things. But, one of the first doctors, we went
through the usual sort of testing, the doctor kept referring
to Terry but I was clearly sitting right there, breathing in
and out, but all of the answers went to my son. Obviously I
would prefer to be addressed myself. It’s difficult to redo
those tests, too. Inviting students in while you’re doing the
testing…nobody’s asked me to do that yet, but I have my
“no [answer]” ready if and when they do. There needs to
be a connection with the patient, just don’t leave us hang-
ing out on a limb for answers. We perhaps we don’t under-
stand as readily as we once did, although I’m not quite

Daniel Kuhn: Marty, as you can tell, has had some
very interesting experiences and he’s got some very good
ideas about how we can make the world a friendlier
place to those with Alzheimer’s disease. I would really
like to involve him in some of those efforts to change
public policy and he’s very eager to join in that effort.
But, I want to go back to the question about the testing.
Joan, for example, you had gone through a period of test-
ing and can you make some remarks about what that
testing process was like for you?
Joan Cahill: I admit to not being able to read as much as I used to.
Takes me forever to read one book, where before I used to
read at least two books a month. Some of those things you
can cover up for a while and make do with, but others
you’d like the horse to get out of the stable and get on with
whatever it is we need to do and just the ordinary things of
everyday living.

When we start to this it would have all gone away and life would
be what it was. I don’t drive anymore at all Voyer. I don’t
have the response time and all the rest of it. So, that was
very firmly suggested early on, which is still now and will
be until the day I die. driving me crazy. You can’t just pick
up and go when you want to. I have all kinds of people
who have cars and are willing to help, but they also have
lives of their own. You have to have a car for every single
ting you do.

Daniel Kuhn: I think your experience of being tested
and being treated almost like an object is fairly typical of
people that I’ve talked to. It’s really unfortunate and it
needs to change. I’m wondering about your reactions to
the diagnosis because Alzheimer’s disease or dementia is
still considered a dirty word in our society. I remember
one day Marty telling me, “It’s just a disease. It’s nothing
to be ashamed of.” I’m wondering Voyer, what was your
initial reaction to your diagnosis?

Voyer Howell: I said it’s like a cold. It’ll probably
give away. I won’t pay much attention to it. I’m still going to
do what I want to do—I’m going to drive my car. But I learned
that I shouldn’t do these things.

Daniel Kuhn: So you were fairly unbiased Kathleen,
what about your reactions?
Kathleen Hutton: I don’t think I was particularly sur-
pised. Enough things had happened that were pointing in
the direction that the doctor concluded. I will say, how-
ever, that the medical people that we see have been very
good, very understanding. They have respected Voyer. They
speak to him, not to me. Another thing I’d like to add in
praise of my husband. He didn’t believe it at first, of course,
but as he thought about it he began to see what he had
done and what had happened to him and he became this
big advocate for not driving. He went through all of these
instances of problems and he concluded that this is not a
good thing to do and probably not a good thing for other
people with Alzheimer’s to do. He worked his way through
that and I don’t know that everyone could do that. I’m really
very proud and certainly pleased that he could do that.

Daniel Kuhn: Yes, thank you. Now let me ask Terry or
Joan Cahill before turning to Marty and Laurie Bahr.
Could you talk about your initial reactions to the
Diagnosis or your family’s reaction to the diagnosis after it didn’t turn out to be depression and they finally put another label on it?

Joan Cahill: You know, I don’t remember, and maybe it’s just another one of those “I don’t remember” things. But I don’t remember anybody actually saying you have dementia or you have Alzheimer’s disease.

Terry Cahill: We switched hospitals and now mom is getting good care. We went through a couple different rounds of testing and the first real words we got were “mild cognitive impairment.” I think part of us, our family, hung on to that meaning. Like that’s not Alzheimer’s then, right? Does that mean it’s not going be that bad, then or will not progress as fast?

We were trying to weigh between dementia and depression—and both are there—that makes it even more difficult. As time’s gone on and I’ve talked with my brothers and sisters, it’s just become more obvious that it’s more than depression or lack of concentration. It has been a process over time.

The moment that stands out in my mind that showed that we were all on board with the fact that mom’s got dementia, was when we had to take my mom in for emergency heart surgery. Actually it was for angioplasty and when the doctor came out to talk to us about the fact that they were going into an emergency procedure, he was a doctor that my mom had known for some time and he started to say things like, “There are implications for potential aggravation of memory problems.” And he walked around it so cautiously because he didn’t know that we knew that my mom had some issues going on. Then he was able to say that he worked on a board with my mom and that she doesn’t seem to be the same as she was. That was the moment when it was clear.

Daniel Kuhn: How about for you, Marty and Laurie? What was your original reaction to getting this diagnosis?

Marty Bahr: The first thing is, “Are you talking to me? This can’t be. I’ve been “successful and… The first thing for me was denial and then after a while with the help of Laurie and my kids I think they knew before I knew or accepted it. Even today I have some difficulty with it…” Why me?” and things like that (Figure 4).

Laurie Bahr: Because of us being so young, it was more shock and disbelief because you more associate this with being an elderly or an older person’s disease. You go through the shock element of it. Especially when this physician first revealed it to us and I’ll never forget that evening. He walks out of his office and says, “Yeah, it’s a bum deal and we don’t know what we can do for you.” I was thinking, “My gosh, we’ve been sent out into the world, having been told this, no resources, don’t know what do…” Oh, he did mention that there are a few medications available that may slow the progression of it. He said, “I’ll have to look those up.” We were incredulous. We were in shock. You have to go through all stages of the grief process, all of the psychological issues.

We were living in the state of Washington at the time and eventually we were referred to the University of Washington Alzheimer’s Disease Research Center and then it was absolutely confirmed that yes, it is Alzheimer’s disease. As we were saying earlier, there were no driving incidents, no getting lost, the signs are very subtle, such as vision processing. In retrospect, when we began to put two and two together, that’s when we realized why he was having the problems with the computer; that’s what began to show itself before anything else did.

You go through shock because of his age. I found over the last few years that you have to let yourself go through all the stages of grief and just accept the fact that this is just part of your life now. We now have the best medical care and what more can we do?

Daniel Kuhn: Marty, can you talk about how your perceptions about Alzheimer’s disease have changed over time because initially you associated it with something devastating. I recall in a prior conversation you thought you were going to die. Over time, obviously, that prediction didn’t hold up. So, can you talk about what has happened over time that has changed your mind about what it means to have Alzheimer’s disease?

Marty Bahr: That’s a really good question. I think, first of all, you have to be true to yourself and that was the hardest
part. As far as kind of wrapping your arms around the situation and knowing that I have a problem, I would say that Laurie's been absolutely incredible. I'm very fortunate and... here's where I lose my thought...

Daniel Kuhn: You talked about coming to terms and Laurie's help with that.

Laurie Bahr: (also to say to me) At first you thought you were going to die. You went through that a lot and... Marty Bahr: That phase there's no answers and so you think you're going to die, and, unfortunately, it's another one of those situations with doctors. Some doctors tell you the wrong things or do not handle it the correct way.

Laurie Bahr: How do you handle it on a day-to-day basis now?

Marty Bahr: On a daily basis, it's pretty easy because I'm at home most of the time. I can't read very much I spend a lot of time contemplating me I guess. But it's a beautiful place where we live and I take long walks and do not get lost. I have a dog... a very slow dog (laughter). Even too slow for me! I knew somebody was thinking that. On an everyday basis I think I do pretty well. I just can't drive. Driving is totally out of the question. It's too dangerous.

Laurie Bahr: Do you feel frustrated? How do you deal with the emotional aspect of it, for instance? How is it different today than it was earlier on?

Marty Bahr: I have a short fuse. I've always been a go, go, go type person, very successful. It's very difficult when Laurie's not there. It's me and the dog and between the two of us, we work things out. It is very difficult when you're alone. In my case it's the eyes, I get tired.

I feel so guilty that our caregivers work so hard plus what they're already doing and it's a great burden along with all of the other things they have to deal with. Sometimes, I just can't do it. We've seen it today; I was all prepped and ready to go, and, believe me, I'm usually not short of words, but I just have to turn it over to Laurie sometimes because I just kind of forget where I am. Now I could go like gangbusters, but I'm not gonna bore you. (laughter)

Daniel Kuhn: I've seen him in action, and sometimes there's no doubting him up (more laughter).

Marty Bahr: Does that answer your question?

Daniel Kuhn: Yes, it does. Thanks Marty. Kathleen, you wanted to weigh in about how your reaction has changed over time?

Kathleen Hutton: It's related, I guess, to something that Marty touched on before. If you listen to Voyer, he's very verbal and people have a hard time believing that anything's wrong with him. (Voyer offers a wicked laugh.) Marty talked about being in the airport. Well, we've traveled a great deal since the diagnosis while we can. I've found myself saying to security people, 'My husband has Alzheimer's so please let me be with him, because it's hard for him to get his shoes off, put them back on. Before I told them this, they would say, 'Don't go near him!' It's very difficult dealing with those types of things. Voyer's children had a hard time with it, too, because they live so far away. Because he sounds fine on the phone, for a while they would say to me, 'Are you sure something's wrong with him?'

Laurie Bahr: Yes, Marty's daughter took a while, too.

Kathleen Hutton: I really admire people who will say, 'I have Alzheimer's.'

Laurie Bahr: To Kathleen's point, one time Marty was traveling where he had to make a connection and I called up the airport and asked if they could escort him and they said, 'I'm sorry, Alzheimer's is not on the list of disabilities that we'll do that for.' There needs to be that kind of education or message that gets out there to the world, in general, that this does exist.

No one suspects that this can happen to someone under age 60, and even with those individuals, when the time comes that they are diagnosed, you have the denial aspect of it. We've been told that Marty is in the minority. He has no issue saying to anyone, anywhere, 'Hey, I have Alzheimer's, could you please help me.' There needs to be more education that is brought out there to not only the health care industry, but everyone else. That people with Alzheimer's still interact and that there are services that they still need.

Daniel Kuhn: I saw Terry nodding when you were discussing reactions by other people. Do you want to say something about that?

Terry Cahill: Just that our own acceptance process of this is difficult enough. When we got our first full report back that said my mom had dementia, her primary care physician told her, 'You don't have dementia and you'll never get it!' Very definitely. So, we were trying to work with it dementia or depression? And we were also fighting with the doctor that my mom had a long-term relationship with so it was difficult.

There's a picture or stereotype in people's heads that they're looking for. My mom is still very confident and able to have a conversation and enjoy things, so therefore it appears as though she doesn't have dementia.

Laurie Bahr: We've run into the same thing, even disbelief among physicians. Again, because of his [young] age.
Joan Cahill: Well, I think that’s the background of my generation. I guess. You keep your business to yourself. Yeah, I’m uncomfortable with it. In fact, I got a phone call several weeks ago. No, wait, it was longer than that. It was last November, to my surprise, it was that long ago. A gal that I worked with for the last several years at the hospital…

Voyer Howell: I think talking with everyone individually, transportation really does stand out. Marty, bow about for you? What would you be interested in doing close to home on a regular basis? Is there some specific activity that you would like to do?

Marty Bahr: Yes, all of the above or anything else that would be of help to Alzheimer’s patients. There is a support group that I’m helping form with Rush (Alzheimer’s Disease Center).

Laurie Bahr: It’s a support group for younger people with Alzheimer’s. One idea you had mentioned, Marty, was having mental brain exercises in a group that got together periodically.

Marty Bahr: When I first got involved, a support group did not fulfill my expectations. I just wasn’t to that point. We talked about it and decided that I should be doing something else.

Laurie Bahr: You’re trying to form a group for early onset Alzheimer’s patients and you still want to be part of trying to find solutions, trying to change public policy, to try to get the message out there for those with the same needs as you. What about volunteer opportunities?

Marty Bahr: Yeah, I think volunteers are great and I’m all for it, but I could do a lot more if I had some way to get around. It’s expensive. Someone should look into that. It’s so important. There should be some activities where you can develop friendships with other people and talk about what’s going on. Everybody I’ve met has been wonderful. There just isn’t enough out there.

Daniel Kuhn: In private, we’ve talked about how adult day centers are not geared toward people with early onset Alzheimer’s and somehow we’ve got to raise the funds to create specialized programs. Coupled with that, of course, is good transportation. I want to turn now again to Voyer In spite of your limitations, what are some of the blessings that you have found in dealing with this disease?

Voyer Howell: My wife bakes wonderful pies. No, seriously, my being involved with the Alzheimer’s group reinforces my beliefs. I’m not a person who believes in dying. I know I’m going to die, but not today. I want to share that message with others and make each day count.

Daniel Kuhn: Make today count.

Voyer Howell: My ambition that I have now is not so much to say that I want a cure, but I want to live my life as much and to continue doing the normal things, dancing, bowling. I would encourage those, and I assume some get tired of me saying it is, ‘Cheer up! Don’t worry about death—live until you die!’ That’s my theory—that’s my belief.

Daniel Kuhn: Thank you, Voyer. That’s great advice.

Joan Cahill: I’m not very far into it, actually, I still think sometimes if I hadn’t paid any attention to this damn stuff, I would not be sitting here today. The most evident return has been a very marvelous one. I think how attentive my children are. I’m still on some level… it isn’t that I don’t think I’ve got it (Alzheimer’s), it’s just that on one level I haven’t made peace with it. I guess.

Daniel Kuhn: Thank you for your honesty, Marty, bow about you? In spite of the limitations, are there any blessings you can identify right now?

Marty Bahr: I think at first it was hard to find any. One of the major blessings I think is meeting people that have the same problem. ‘Misery loves company’ is a terrible thing to say, but, in this case it’s true. It’s difficult for me to have discussions for the other parties up here because we live far away from each other and we don’t have the same
symptoms, so sometimes it seems that you’re out there on your own. One of the blessings is being here in Chicago. Meeting people like you folks who are here and seem to have a need to help other people. Those of you that are here are not looking for a return except to help with Alzheimer’s.

Daniel Kuhn: The final thing I want to address today is a question of hope. What do you hope for?

Marty Bahr: I seem to be doing all the talking here... I still believe that I’m going to be better. I still have a lot of things that I can contribute to the world.

Daniel Kuhn: You told me once that of course you hope for a cure, but what if it doesn’t come in time for you? What do you hope for then?

Marty Bahr: I hope that I can somehow help others, that I can help others understand what we’re going through and to help people go through the denial I think having people like everyone in this room makes it easier I also want to thank Dan. He was over at the house and took a lot of time with us and I really consider him as a friend.

Daniel Kuhn: Really, the pleasure is mine. I want to ask Joan and Terry, what do you hope for in relation to Alzheimer’s disease and your life?

Joan Cahill: I think it’s heartening that there’s a decided increase in the number of people who have a vital interest in Alzheimer’s disease. I’m not expecting a cure in my lifetime. Oh, and I hope I don’t live for another 20 years (laughter) that’s just sort of sounds untidy somehow. (more laughter)

It’s heartening to see that people are working on it. I’m grateful to all my children—they are a big part of why I keep moving. And once again, thank you for this opportunity.

Daniel Kuhn: Voyer, what do you hope for?

Voyer Howell: Oh, I hope to be an instrument to encourage men and women that life is beautiful and live it to the finish. Not to worry about dying but to learn how to live it to the fullest and that’s what I’m doing with my wife, my lovely wife… isn’t she beautiful? Do you think I’m gonna die and leave her to someone? Oh no... there’ll be a ruckus in hell (laughter) I’m sorry, what I mean is... (more laughter).

One last thing I can say is that I hope the remainder of my days is in helping people in whatever situation, whatever knowledge I have to bestow it on or if I can uplift someone, then I’ve done a good job. It’s not about ego or medals I get the medal when I see the smiling face and I say: ‘Hey, how are you doing?’ If they say: ‘Not too good’, I’ll say: ‘Well, then let’s go bowling or how about going to the ballgame?’ That gets’ em. But, anyway that’s my desire—to live and learn and to pass it on to others.

Daniel Kuhn: Thank you, Voyer, and thank you all for your participation today. We will now end with a tribute to people with Alzheimer’s disease through pictures and music. Please watch and listen.

Finally, photos of people with Alzheimer’s disease appear in a PowerPoint presentation accompanied by the song, “How Can Anyone?” performed by Shaina Noll and Richard Noll from the recording “Songs for the Inner Child.” The session ends with a long, standing ovation by members of the audience.


This panel session, “Voices of Alzheimer’s Disease,” is available in DVD and VHS formats by calling 1-800-223-4406. Copies are available for $35.00 each sent to: Alzheimer’s Association, National Distribution Center, PO Box 930408, Atlanta, GA 31193.

Address correspondence to: Daniel Kuhn, MSW, Mather LifeWays Institute on Aging, 1603 errington Ave, Suite 1800, Evanston, IL 60201. E-mail: dkuhn@matherlifeways.com.

The Voices of Alzheimer’s Disease