

NATIONAL PRESS CLUB LUNCHEON WITH ACTOR MICHAEL YORK

SUBJECT: CHALLENGES OF AMYLOIDOSIS

MODERATOR: THOMAS BURR OF THE NATIONAL PRESS CLUB

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THOMAS BURR: [sounds gavel] Good afternoon, and welcome to the National Press Club. My name is Thomas Burr; I'm the Washington correspondent for the *Salt Lake Tribune* and the 109th President of the National Press Club. Our guest today is Michael York, the famed stage and screen actor. I would like to welcome our Public Radio and C-SPAN audiences, and I would like to remind you that you can follow the action on Twitter using the hashtag #NPCLive. That's #NPCLive.

Now it's time to introduce our head table guests. I'd ask that each of you stand briefly as your name is announced. Please hold your applause until I have finished introducing the entire table.

From your right, John Hurley, a former White House correspondent for the McClendon News Service, and a former commander of the Press Club's American Legion Posts; Emily Whitten, a columnist for ComicMix and a senior attorney for the Department of Labor; Ferdous al-Faruque, medical device reporter for MedTech Insight and a Press Club board member; Dr. Victor Wahby, medical director of the Medical Music Group, who was recently on the cover of the *Annals of Internal Medicine*; John Griffith, a producer and director; Deana Martin, singer, actor, author, performer and – one of my favorite parts – the daughter of Dean Martin–

DEANA MARTIN: Thank you. Are you going to say it?

MR. BURR: Ain't that a kick in the head. [laughter] We were talking about that earlier.

Donna Leinwand Leger, breaking news editor for *USA Today* and a past Press Club president. Skipping over our speaker for just a moment, Dr. Christine Warnke, host of Next Word TV, Channel 16, MMC-TV, and who invited our speaker, I believe today, thank you; Pat York, a photographer and the better half of Michael York [laughter]; Fran Marie DiCinto, the Twitter champion for the National Press Club [laughter].

Thank you all. [applause]

British actor Michael York began to notice disturbing symptoms in 2009 when he had to use more stage makeup to cover up dark purple circles under his eyes. Over the next few years, he frequently felt ill and tired. York received several misdiagnoses. After treatment for bone marrow cancer did not help, York's wife Pat sought out a bone marrow cancer expert at the Mayo Clinic in Rochester, Minnesota. That doctor, was also an expert in amyloidosis, a rare and potentially fatal disease. It turned out that amyloidosis was the correct diagnosis. It's caused by the abnormal production of insoluble proteins that clump together in different parts of the body. It can cause vital organs to shut down.

Four years ago, York underwent a stem cell transplant at the Mayo Clinic to remove some immature blood stem cells. It was followed by chemotherapy to get rid of diseased or damaged marrow. Then the treated stem cells were reinjected. The treatment worked. Although York still has the dark circles. He often jokes that he is available for movie or stage roles for older men who wear dark glasses. [laughter] So if anyone is doing a Mafia movie, you know who to call.

York's acting career spans 50 years, and includes roles on stage, film and television. He is in Washington this week to celebrate the work of the Medical Musical Group, whose mission it is to provide healing through music. It's a chorus and orchestra made up of healthcare professionals. They are performing Sunday in Alexandria.

Please give a warm National Press Club welcome to Michael York. [applause]

MICHAEL YORK: Thank you. Thank you so much. You realize you've stolen the best part of my speech, which was to inform you all about amyloidosis. Because most people say "what?" when you mention you had it. So I thought I would give you a sort of overview. Because we have the C-SPAN cameras, these next 20 minutes could save lives, because for the most part this disease goes unrecognized, misdiagnosed, whatever. It was the orphan disease, hiding in the shadows. It was the Rodney Dangerfield of diseases; it got absolutely no respect. But now things are changing, and thanks to your invitation, I hope we can really change them.

I don't want to get into too many details, but basically what happens is that— [phone rings] hello? I'm available if that's a major role. [laughter]

Normally, proteins, which are normally produced, they fold naturally and the body uses them, gets rid of them. Some proteins misfold, for whatever reason. And again, this is a mystery. The research is going on. Why does amyloidosis occur? And these proteins, these fibrils, amyloid, a Greek word— when I say, oh, yes, it's all Greek to me [laughter] — they accumulate this sticky substance and they get deposited in major organs silently — the heart, the kidney. So many places are vulnerable. And they slowly shut the body down.

Now, the statistics are fairly alarming, and I want to do them justice. It's a very rare disease. That's why recognition and diagnosis, you're lucky if you get it. It's one in 100,000 people get it. And in the States and in Europe combined, 150,000 people, which is nothing.

So to get the research funded for this rare disease is not that easy. But Ann Philbin, who's here in the room, is addressing— one of the great amyloidosis survivors, pioneers. Ann, where are you? There you are. Stand, please, because this— [applause] This extraordinarily courageous woman, who's undergone two stem cell transplants, has been battling the disease, and will be addressing the National Institutes of Health on the need for more funding, more recognition, more this, more, more, more. So thanks to people like you, the word is getting out.

Let me give you a few more statistics. No, that's boring. [laughter] I wrote a book about this, the whole experience. It's at the publisher now. The agent is taking it to the big houses. I'm not sure it's for them, you know, the Simon and Schusters who have done previous books of mine. So anyone out here who knows a little publisher who might be interested in this; a niche, in other words. And it's called *Amyloidosis: An Odyssey of Healing: From Mayo Clinic to John of God*. There in the title suggests how I approached it.

For me, healing was a mystery. And there wasn't a one-size-fits-all solution. So I'd been a homeopath for 50 years. It worked for me very well, naturopath. So when I suddenly had to take a lot of drugs, with their alarming side effects — and there are. Because I was treated for multiply myeloma. And as you've heard, it wasn't the right solution.

So I wanted to explore the alternatives. I did go down to see John of God, the great Brazilian healer, and was helped a great deal. So the nature— here were are, in the great world capital, with the greatest hospitals in the world, and so on, but it's not a solution for everyone. I think you have to find your own way.

When I first got sick, someone sent me a little notice. They said, "Don't forget: you cure you." And I took that to heart. And I've been very lucky; principally, having a wife who refused to take no for an answer, who just refused to be blindsided or put off until, as she said, she found the miraculous Dr. Kyle, Robert Kyle — God, he's almost hitting 90 now — who invented so many of the protocols, who very calmly said, "I think you've got amyloidosis." And from there, into this period of recovery.

At the moment, it's incurable. You get these breaks and you're very lucky if you can do a lot of things in the breaks. I'd been shut down. I couldn't perform, I couldn't travel. I couldn't do all the things that I love. Now I was able to. In January, we were in India. I wanted to explore the protocol of Ayurveda, the ancient Vedic Indian healing system. They've had a protocol for amyloidosis that is two millennia old. So I thought, well, they may know something.

All these can be integrated. And as we can all tell you, the side effects of so many drugs, you wonder if it's worth going through it. But great work is being done.

So anyway, back to the fact sheet. I want to hit you with these. These are from our action group, the Amyloidosis Research Consortium, run by one of the other great heroines, Isabelle Lousada, who's tireless in her efforts to getting the word out.

Anyway, so 3000 patients are diagnosed each year in the US with amyloidosis. They're the lucky ones. Seventy-four percent of all patients have cardiac involvement. So if you have any friends or you know of anyone who's having problems with their heart and they're not getting results or they're not getting satisfaction, as the Rolling Stones said, have them checked out for amyloidosis. You'd be amazed.

Okay, four is the average number of doctors patients see before being diagnosed properly. Forty percent die because diagnosis comes too late to benefit from treatment. That's appalling. I know too many. And that's why I'm so anxious to get it out. And thank you.

This really, this hits home: Out of 443 patients, 220 cardiologists missed diagnosis. That's an alarming figure. And 1500 cases are missed by cardiologists in the US each year.

So as I said, go for it.

Thousands die never knowing they had the disease. So Ann and I are convinced this is a vastly unreported illness. So we want to do everything in our power to change that statistic. And things are happening. The little orphan now is being ushered out of the shadows into the spotlight. It's our moment.

And in the three years of remission I had before things started to – you know, they changed again – they've started working on, the first time, remedies directed directly at amyloidosis. Before, we had to use the castoffs from multiple myeloma. Now places like Prothena Labs in San Francisco, they're going all out to provide us direct remedies.

I also went to Britain, where, at the Royal Free Hospital, the National Amyloidosis Centre is centered. Fantastic work going on there. Sir Mark Pepys has a diagnostic machine. You get in it and you can – it's sort of nuclear medicine, to determine

the amount of amyloidosis load you carry. Again, wonderful work there. GlaxoSmithKline combining on research.

So we're all very excited in the amyloidosis community, that things at last are happening. As Shakespeare said, there's a tide in the affairs of men, which taken at the flood, leads on to fortune. And I think that tide is beginning to flow.

I've covered a lot of ground. [laughter] I've talked myself out. So anyway, the chapters in the book, I tried to be a bit fancy-pantsy literary about it. And the one that I chose when things started to go wrong was that great quotation from— from who? Sorry, cut this bit out. [laughter] Which of course you can't. From Dante: In the middle of the journey of our life, I found myself in a dark wood where the straight way was lost. That's exactly what it felt, where you didn't know where you were going, everything was dark. And as I said, the middle of our journey of our life; it does tend to happen to, shall we say, maturer people, this disease. Although alarmingly, it's now being found in the younger population. So we're not immune. As I said, one size doesn't fit all.

But anyway, as I said, I think the best thing I can do is, instead of whittering on here, is to answer questions more specifically of maybe things that have come up in this address that puzzled you or have prompted further questioning. Is that all right?

[applause]

MR. BURR: Thank you, Mr. York. We have a lot of questions, so this is good. Some dealing with the disease, some dealing with your acting career, of course, and some relation between the two, actually.

MR. YORK: Some would say it's the same word, disease. [laughter]

MR. BURR: Let's start with this. So the question would be: What can be done to further awareness of amyloidosis?

MR. YORK: Well, it's, again, it's a grassroots thing. Maybe you'll go home and mention the word, our C-SPAN listeners will mention the word to their friends, who will mention it. And that's how it gets around. As I said, it's no longer the anonymous orphan. It's out there. And the great thing is, to get it to your cardiologist. I was getting— I'm having cataract surgery. And I was at a very distinguished LA hospital last week. They want a fitness test before they do your eyes. Why, I don't know. But anyway, this guy saw that I had the darkening of the eyes and he said, "Well"— I said, "Don't worry, it's amyloidosis. It's a blood disease." And he said, "Well, we'd better biopsy that." I was like, "No, don't you dare." [laughter] "No, no, a blood test."

So there, a leading member of his profession in a leading hospital, again, was not sure what it was all about. So all our educational efforts are as much for the medical profession as for anyone else. That sounds terrible to say that, but there is a need.

MR. BURR: Sir, we're about two blocks from the White House. You're in the seat of the United States government. In your opinion, what can the US government do to help find a cure for amyloidosis?

MR. YORK: As Ann has petitioned them, research, funding, awareness and money. And Robert Kyle, up at the Mayo Clinic, a man who should be lauded, crowned with laurels, he keeps saying, "But we don't get the money to take it further." They seem to think that funding belongs elsewhere.

I'm partially inclined, I think they're wrong. This is something I think that is huge. And worldwide, we don't even, can't begin to assess the statistics. But Europe and the States do have statistics.

So I think that's the way to go.

MR. BURR: You talked earlier in your speech about the misdiagnosis that happens often. So what type of specialist should the first choice be for someone who may suspect they may have amyloidosis?

MR. YORK: Well, here are the symptoms in a nutshell. Typically, patients will have some of the following symptoms: unexplained weight loss; fatigue; shortness of breath; foamy urine; swelling of the ankles and legs; as well as numbness and tingling in the hands and feet. These are the manifestations of damage to the underlying organs from the insoluble amyloid protein.

MR. BURR: The question is about who should they see first. If you see those symptoms, who should they go to? What kind of specialist would you recommend?

MR. YORK: They might have a very enlightened doctor who's aware of amyloidosis. They do exist. And more and more as we bash them over the head. [laughter] So yes, their primary care physician, and then if they're not getting satisfaction, go to a hematological— is that? Hematology specialist, who maybe stands a better chance of being aware of the issue.

MR. BURR: I'm still trying to pronounce amyloidosis correctly, sir. Just for the record. [laughter]

MR. YORK: It's all Greek to you as well.

MR. BURR: Exactly, always is. Have you been able to recruit other celebrities to the cause? And do you find that helps open doors to you, that a celebrity has that other ordinary people may not have?

MR. YORK: Well, yes, I was always in two minds about this issue of celebrity. Because we're all celebrities now in our media world. But I think if it can be used, like Michael – I'm trying to think. Thank you – Michael Fox. A wonderful example. Putting

the spotlight on a disease. I think it can help if it gets you in the door. If you've got a body of work that has been well received, then people will tend to receive you better.

So I don't care. I mean, for me, this is the best role I've ever been given in my life, because it's important. Not that I'm denying the work, which I love; I've spent my life doing and I'm so grateful to have had a consistent and life-enhancing career.

MR. BURR: Let's follow on that for a second. There are a lot of celebrities that we worship in some ways. What do you say to your fellow celebrities about getting out there and promoting their own causes and making sure they're using their fame for the right purpose?

MR. YORK: Well, I certainly would never lecture them, I wouldn't dare, that they should do this. But I think people are aware of this. I live in Hollywood, so I know a number of people, as does Deana, a number of people we know who are involved in causes. Not even with their names on it, but just as a tremendous sense of having to give back if you've been fortunate. And I think people get a tremendous satisfaction from that. Though we love being performers.

MR. BURR: I think the question is, you didn't speak about this obviously till you had it; you didn't know about that. But there are a lot of younger celebrities out there that we see on TV all the time. There are great causes out there that need somebody to speak for them. I'm asking you if you would encourage them to do so.

MR. YORK: Yes, I would. I was approached by a wonderful lady, Muriel Finkel, who runs the Amyloidosis Support Groups. And there are these groups. There's the Amyloidosis Foundation, Muriel's group. She said, "We were waiting for a celebrity who would agree to do this. And I'm sorry it had to be you." [laughter] "But thank goodness you're willing to share." And of course, Muriel, it goes without saying.

MR. BURR: That's great. So the Office of Rare Diseases at the National Institutes of Health just up the road a little bit plays a key role in identifying research activities for rare diseases. Were you able to interact at all with that office, as well as the National Organization of Rare Disorders?

MR. YORK: No, but I know people in authority who are. We're well aware of it. It's in our literature. Certainly there are these facilities and resources available. It's just about getting the word out. And it's happening. For me, the future is incredibly positive. And I think even this lunch, as I said at the outset, possibly could have saved a few lives of people recognizing what's not right, what is right, and so on. So I'm all for that.

MR. BURR: Let's talk about another lifesaving organization. Can you talk to me about the role of the Mayo Clinic in helping diagnose your disease and others?

MR. YORK: Well, the Mayo Clinic, as you know, founded by an Englishman [laughter] with these wonderful nuns, is the most extraordinary place. I mean, it's the sort

of mother ship of hospitals, for me. I could go to Cedars-Sinai, a great hospital, ten minutes away, but I schlep to Mayo because I like it. I love the doctors there; they're all my friends now. I admire them inordinately for what they do, because they all— you find the doctors at City of Hope, whatever, Cedars, they will go out and speak about this. They put themselves— they not only do the work of doctoring, but they go and do the work of promoting the cure of the disease.

MR. BURR: So this questioner notes that he or she has cardiac amyloidosis and wants to know—

MR. YORK: Someone here?

MR. BURR: Someone here, someone who wrote this question. The question is, do you have any thoughts on— right here in the back. Do you have any thoughts on the increase and the availability of experimental drugs to treat the disease? I assume by that, there are cost factors, there are availability factors.

MR. YORK: Yes, I mean, one of the greatest drawbacks is the disease is so relatively rare and to put enormous investment in a drug trial for a rare disease, I think that's asking a lot. But there are companies doing this. I'd love to hear your point of view.

MR. BURR: Maybe we can have that conversation offline, sorry, for camera reasons.

MR. YORK: Oh, that's right, yes. Forgive me. I hope you're getting better.

MR. BURR: I'd be glad to introduce you right after.

MR. YORK: Okay.

MR. BURR: You kind of brought this up a little earlier, sir. Part of the diagnosis to confirm amyloidosis requires a tissue biopsy, which can be risky for older patients. Do you know of any research to develop less invasive tests for the disease?

MR. YORK: Well, you can get it from the blood. That's the basic thing. Because it's about the light-chain disorder. Sometimes the heavy-chain, but it's principally, in AL, they call the— primary amyloidosis is AL – A for amyloidosis, L for light-chain – which affects about 85% of amyloid sufferers. Sorry, what was the question?

MR. BURR: Finding a less invasive test.

MR. YORK: Oh, yes. As I said, get a urinalysis and a blood draw. But actual tissue, I've never been asked for that.

MR. BURR: I'm not sure who made the question. I should have followed up on this a minute ago, actually. This is a great question. How can we incentivize drug

companies to invest in research when it comes to rare diseases? Because obviously there's not the mass marketing of drugs that can happen with those, but people are still dying. How do we incentivize drug companies?

MR. YORK: Well, I mean, making a buck is what it's all about. And God bless them, that they're doing it. I think the National Institutes of Health should be leading the way, beating down the doors, and being very proactive, because the nation's health is involved. And I think from my point of view, a bit of government involvement can be a great thing.

As I said, back in Britain, it's all the National Health; it's part of the government deal. And they're doing great things. But getting also drug companies involved in their studies, it's of mutual benefit to each. Because you hit on that drug, little purple pill, or whatever it is, you stand to make— to get back your investment, certainly.

And we're talking long term here. And as we're convinced that suddenly we'll realize that there are many, many more sufferers than we realize, that all those mystery illnesses and whatever have gone misdiagnosed too late.

So I'm not the person to ask. I'm not a businessperson. I'm not a doctor. I just pick up these little pieces of information and hope I can pass them along in intelligible form.

MR. BURR: Well, since we're here in Washington, I will ask you somewhat of a political question, because you just talked about the National Health system in Britain. How has Obamacare affected rare disorders like yours? Has there been any assistance from that? Or should there be more put in from some kind of legislation?

MR. YORK: You know, that is a great question, and I wish I could answer it properly. But I can't. I don't know the answer. And maybe someone here does. I would like to think that Obamacare has helped in the collective spotlight on the answer. I wish I knew. It's a wonderful question. And I wish you asked me that yesterday. [laughter]

MR. BURR: I'll ask you afterwards. We can tweet it out. Even with amyloidosis, you have continued with your career. How have you managed to do this facing what you have? And what future films or television performances are forthcoming?

MR. YORK: Well, I'm afraid my career has been very much sidelined with our other priorities. I remember when I was with John of God down in deepest Brazil and actually going through a tremendous detox. I could barely move. I, in ten days' time, I was giving a performance here in Washington of *My Fair Lady*, Colonel Pickering. I said to John of God, "I hope this is not out of line, but could you help me. I have this performance in ten days' time and I can barely move now." He said, "Yes, it's not inappropriate at all; I'd be happy to help you." And I must say, I shall never forget the performance here at the Kennedy Center, because it was such an affirmation. Being back on the stage and having to sing a song that went, "Tonight, old man, you did it!" And the old man was John of God, it was Dr. Kyle, it was every doctor. That was great.

MR. BURR: Anything forthcoming, sir?

MR. YORK: Well, I just did another *Simpsons*. [laughter/applause] Thank you. That, believe me, is true fame. [laughter] The only time my grandchildren looked at me with any sign of respect. [laughter] But it is nice. I'm slowly getting back. Everything in contrast to this seems important, but this seems to me totally important. So if I can give whatever energies I have left, and time I have left to this, I shall be a happy man.

MR. BURR: I had drinks with one of the producers of the *Simpsons* here recently, trying to get him to put the Press Club into an episode. So if you'd like to— [laughter]

MR. YORK: [laughter] I'll remind them.

MR. BURR: Thank you, sir. We talked a little bit about this, but tell me what effects of the disease affect your everyday activities. And how do you deal with those effects?

MR. YORK: Well, obviously, my voice is coming back, but at one point it didn't. I voiced a little animated, not a cartoon, but— it's wonderful. Go to it online. It's about every case of amyloidosis, done in very accessible form. Translated into 14 languages. So it's a real asset.

But I do what I can. And as everyone knows, we never quite know what's coming next. But we're prepared for it. So I'm prepared for whatever comes along next.

I've been involved with film scripts I've read. But I work very hard for— I was very lucky to start young and I really loved what I did, so I spent the whole time, as much as one can, because there's no guarantee of anything as an actor. If you do A, B doesn't follow; more likely, Q.

So I've got so much to be thankful for. And particularly with regard to this. This three-year remission has been fantastic. We're traveling again. No, life is good.

But you're obviously aware of the dark things in my eyes. I said to Pat this morning, Look, do you think I ought to cover it up? Put a dab of makeup on? I'm on television. And I thought, no, this is what I am. As Popeye said, I yam, what I yam. [laughter] So good or bad. These glasses are cosmetic, meant to hide a multitude of sins.

MR. BURR: Did you just give us the secret to life there a few minutes ago, with the be prepared for what may be coming? Is that the secret to life for Michael York?

MR. YORK: Yes. And never stop being grateful. And I think be positive. Positivity. I mean, it's all very well for me to say this, but I know this has been said by concentration camp survivors, Holocaust survivors, be positive. I think with that attitude,

great things can happen. And that's why I think politically we're in such a mess, because it's so hard to be positive now.

MR. BURR: Do you want to talk about the presidential campaign? Because we can jump right into that. [laughter]

MR. YORK: [laughter]

MR. BURR: Who are you voting for, sir?

MR. YORK: Oh, God, it's difficult. I'd rather not. But talk about drama. [laughter] No, I won't go there. [laughter]

MR. BURR: I told Mr. York, in anticipation of this luncheon I rewatched one of my favorite movies, *Logan's Run*. [applause]

MR. YORK: Thank you.

MR. BURR: You told me when I mentioned that earlier, there's a connection there between *Logan's Run* and amyloidosis.

MR. YORK: Well, yes. And even more so, a friend of mine, a guy, he wasn't a friend then, but he approached me out of the blue saying, "My name is Paul"—I can't remember it. Paul, forgive me. What is Paul's name? Anyway, it'll come to me. This is jetlag. Paul McComas.

MR. BURR: Paul is very happy out there in TVland right now. [laughter]

MR. YORK: Paul wrote it me. He said, "Look, I've written with William Nolan, who wrote the original script of *Logan's Run*. We've done a sequel. We want you to be in it. It's going to be done for voices first of all, then we'll get into all the other things. But Jenny Agutter, who played opposite to you has agreed to do it." I said, "Well, send me the script. It sounds very interesting." And it was really interesting.

Anyway, getting things on, getting money; it's taking its time. So I said, "I'm a bit worried about the voice because it's not the same as it was in the movie." So he asked me what was going on. I said, "Well, it's something you'll never heard of called amyloidosis." He says, "Yes, I have," he said, "my best friend died of it." I said, wow. He said, "Look, I'd like to help you. Is there anything I can do?" He said, "I administer a very small trust fund, but I'd like to put some money your way. But it has to be in Wisconsin."

So we found a doctor, thanks to help from the Amyloidosis Foundation, from Muriel, a wonderful Dr. Hari at MCW, Medical College of Wisconsin, who's taken us on. We've raised the initial fund. And work is being done. And already the results are very promising.

Anyway, we said, look, we've got to call ourselves something. It has to be from *Logan's Run*. How about Sanctuary?

MR. BURR: I don't think that exists.

MR. YORK: So then we thought another key buzzword from *Logan's Run* is renewal. So we're RENEWAL, based at the Medical College of Wisconsin. And the donation line is open. [laughter] It's a very small, at the moment it's small, but like the Amyloidosis Foundation, which grew from some very concerned people around Mary O'Donnell's kitchen table, creating this, and it's now this very significant health organization.

So it's all there online. Thank God you can say this now.

MR. BURR: Just Google it, right?

MR. YORK: Yes. And by the way, what was the— did you get a cookie?

MR. BURR: Yes, we have a question about the cookie, so I can actually show you. Some of the Press Club members here can see this cookie if you're lucky enough to have one on your table. It's a portrait of you as a young man, but there's a story behind this.

MR. YORK: Yes. You should take this home and frame it. [laughter] This portrait was done by Tennessee Williams. A wonderful man who I got to know very well. In fact, in the early '70s we were doing one of the last plays he did, and all those last works will get reassessed some day. They had written him off as a writer, but they were wrong.

Anyway, it was called *Outcry*. It was a two-character play. So we were on the road. We were actually here in Washington, where I think, was your theatre reporter Coe? Yes. Wrote this dazzling review, which Tennessee gave him the encouragement to go on, as if he needed it from what he'd already given.

But anyway, I found there are whole bunch of Tennessee Williams portraits, so I was thrilled to find out that he'd done one of me. Because we were very close. But Pat was even closer, because when we were on the road, I didn't want to eat beforehand, maybe afterwards. And so, she had the great pleasure to be escorted to dinner every night by Tennessee Williams, who, as a gentleman of the South, he would arrive with a corsage. So she had a glorious time.

MR. BURR: It's a tradition of the Press Club to theme our cookies around our speaker. So cheers to our chef for finding that portrait.

MR. YORK: Yes, and thank you for the other one. This is the Amyloidosis Support Groups badge; I'm wearing one here. So, to the chef, I'm really touched and

grateful to you for going to this trouble. Extraordinary. And I shall personally frame them. [applause]

MR. BURR: As I always say, I will pass it on to the chef. Thank you very much, sir. So this is a great question: What would you recommend to those who have been newly diagnosed with amyloidosis? Or just trying to come to terms with it? Support groups? Literature? You mentioned a few other things. What would you suggest to somebody who's newly diagnosed?

MR. YORK: I'd say how lucky you are. They found you in time. There are the resources out there. As I said, we're all connected to the Internet now. And it's all there. The Amyloidosis Foundation, the Amyloidosis Support Groups. There are little local chapters of this. You must find these out. Because as I said, these doctors will travel, they go and speak. There's, of course, the literature. And sheer word of mouth is getting out.

So anyone newly diagnosed, I will wish them great good fortune. Never give up. Never take no for an answer. And you're now in an era where there are different treatments available. And take advantage of them. The monoclonal antibodies are now in their human tests. And they seem to be most promising. There are lots of other tests going on. And our time has come.

MR. BURR: This question is: Are you currently participating in any clinical trials about the disease?

MR. YORK: Do you know, I've offered to be in clinical trials, but apparently my amyloidosis load is insufficient. Which is very encouraging. It wasn't at one point, my God. But I want to keep it that way, because it can come back. It's not a onetime cure; you've just got to watch it and be watchful. The mystery is being— so there are different types. I don't know if I mentioned them. There's the AL, which is 85%. But there's a familial one, ATTR, which is very common as well. And there's even a senile one, which is sort of connected with Alzheimer's. Which is of course amyloid deposits.

So slowly the mystery is being solved. And it can't come soon enough.

MR. BURR: Did anything in your acting career help prepare you for facing this disease?

MR. YORK: Oh, that's an interesting question. Again, I should have had this yesterday. I would have—

MR. BURR: It's the Press Club, sir. We don't do that.

MR. YORK: —the most brilliant answer you've ever heard. Well, Deana, I think we do get, we have— because we cannot prepare for the future, but it takes us and gives us, I think, opportunities and challenges. We are self-employed. So suddenly losing your income over five years is something you have to address; hopefully you've made the

correct investments. But we do have healthcare, thank God. I've been very fortunate that my treatment is mostly being covered. But as I said, income has been naturally cut off.

But no, I think we don't know what's coming next. So we are always prepared to face the next exigency or the next whatever, encounter. So in a way, being an actor is a good thing for that. And we're very lucky. We performed all over the year, so we get in touch with what's happening elsewhere. Because this is an international disease. But the statistics aren't quite there yet for the rest of the world.

MR. BURR: Let's dispel a couple myths here real fast. One, despite what Wikipedia says, you did not play an ape in *Spaceballs*, correct? The real question I have is actually, can you dispel a few myths about amyloidosis, because I'm sure there are some misconceptions about the disease that people may have.

MR. YORK: It's not infectious. I'm sure there are all kinds of myths. But not playing an ape on *Spaceballs*? [laughter]

MR. BURR: I was trying to make a transition. [laughter]

MR. YORK: That's a great segue. [laughter] No, I mean, I've noticed it, I've tried to get rid of it. I've given up. So I say, Thank you very much, I'm so glad you found me so entertaining.

MR. BURR: And you welcome the checks for the royalty payments.

MR. YORK: [laughter] Yes, exactly.

MR. BURR: You appeared a lot in several movies, television, stage, even audiobooks. What role did you find the most challenging in your career?

MR. YORK: It's always the next one. And the challenge is having a next role. Because I don't know a single actor who thinks that his last job is definitely is last one, he'll never be employed again. So no, it's something you can't sit back on. You have to create opportunities. You're your own best salesman.

People say, well, the agent is going to do it. No, he won't. Or a manager. You do it yourself. It's like what I said about amyloidosis; you cure you. You have to be enormously proactive. Which I don't mind.

What other pearl of wisdom can I—

MR. BURR: Can you tell me your favorite lines from your movies or on stage or TV? Your favorite lines you've ever uttered.

MR. YORK: You are awful. All of these would have made wonderful seamless quotations, beautifully delivered.

MR. BURR: I usually deal with politicians, sir. [laughter]

MR. YORK: [laughter] Oh, there have been so many quotations. And I hope, by the way, you'll come and hear us all with Dr. Wahby, with the Musical Medical Group. [applause] It's this Sunday, and it's honoring the 400th of William Shakespeare, so you're going to hear a lot of Shakespeare. But also honoring our veterans, which we can never stop honoring them enough. So it's this Sunday, four o'clock. And not to be missed.

MR. BURR: I believe you could Google that as well to find out the address. Four p.m. Sunday. So it seems these days superhero franchises are all the rage. So would you like to take on a role as a superhero or a villain in a future movie?

MR. YORK: Well, I'm not sure. I'm sure the— do you know, Christopher Lee, Sir Christopher as he was, is a great, he was a great friend of mine. We were in *Three Musketeers*, fought each other before the days of green screen where it's all done for you, and we really went at each other. [laughter] And bonded. I saw him just after one of the great *Hobbit* films. And I said, "You must be having a wonderful time at your age to be found as this great screen hero." He said, "It's so boring." [laughter] He said, "They put you against the green screen and it's all done for you."

So times have changed. But again, I'm so grateful that we had a chance to have been long enough in the business to have done it the other way. Even in black and white. [laughter]

MR. BURR: The questioner wants to know, *Cabaret* is considered one of the best stage musicals turned into film. It's also one of the most important movies of all time. The questioner asks, have you stayed in touch with any of the cast members from that movie? And have you enlisted any of those cast members to help you promote awareness of amyloidosis?

MR. YORK: Well, I'm certainly in touch with— a great thing happened. Turner Classic Movies decided to upgrade the print of *Cabaret* after 40 years. It had degraded horribly. There was a scratch running through the negative that even the computers couldn't fix. And one sainted individual sat down and hand-corrected every frame. It looks fabulous. And if you haven't seen it, don't see any other version but the new one.

So there was a big launch in New York, and we all went along. And Liza Minelli as there, Joel Grey was there, Marisa Berenson. And it was a joyful reunion because it was an extraordinary film.

The one person who wasn't there was the man, the creative genius behind it all, Bob Fosse. And you have to remember, this was in the days before Fosse was this miracle. He was a director under the gun. His previous film, *Sweet Charity*, had failed. So there were a lot of producers standing around him looking at watches. But we, the actors, loved it. Because he was so— he would take time to get it right.

And I remember, I'd been doing a film in Morocco – I'd always had an international career – before coming to Munich to start work on *Cabaret*. And my agent said, "You shouldn't do this, turn it down." I said, "Are you mad? It's Isherwood, it's a classic." She said, Well. So then I really got down to reading the script. And to my horror, I realized she was right. [laughter] It was basically *I Am a Camera*. All these extraordinary, extravagant personalities are revolving around a blob. No characters.

I remember pacing the rainy streets of Munich wondering what the hell to do. And in the end, I got up courage, and I went to see Bob Fosse, and I said, "Look, I don't want to come off as another of these self-involved, neurotic actors, but I don't know how you play this part." He said, "I agree." So he got Liza and me together during the time when they were laying down the dance tracks and rehearsing. He said, "You're going to sit in a room with Hugh Wheeler" – the great writer, who I'd worked with before – "and you're going to put meat on those bare bones." And that's what we did.

I can't imagine doing the film otherwise. And I see actors who are in the stage play and they say, "how do you play this," and I said you can't.

So it owes a lot to Hugh Wheeler, who went on to work with Hal Prince in all those great Broadway musicals. *Little Night Music*.

So I'm eternally grateful that Bob listened. And also on the set, we were constantly improvising. And to the consternation of the producers. So it was happening all the time.

Yes, I'm so glad it was successful, because it was a great, great movie to be involved in.

MR. BURR: We're almost out of time, but a couple more questions. We go from *Cabaret* to this question. Are you concerned there are a lot more blockbuster-themed movies these days and less art in actual movies?

MR. YORK: Yes, it's a concern of us all. But you know, they're principally there to make money, and they do. When they hit right, they make a fortune. So why would the studios go elsewhere? Why would they fix it if it ain't broke?

So these things– and they are. Unless you're of a certain generation. And there are kids who love these, who go two or three times. And it's a great source of income. I'm not knocking it. Sure, I'd love to be an action hero. Great friends of mine, like Ian McKellen, who at the end of their career they're suddenly huge heroes. It's wonderful. Oh, this business is full of surprises.

But I think at the same time there are little ones that escape, that are made in the old-fashioned way, made against all the odds, made with a small budget, made so you

don't get paid much up front, you're profit sharing. But you believe in it and you put your heart in it. And of course, it's wonderful to do both. Whatever works.

But as I said, I don't think we have the demographic that's going to go to the multiplex five times.

MR. BURR: Before I ask the final question, sir, a quick reminder: the National Press Club is the world's leading professional organization for journalists. We fight for a free press worldwide. For more information about the Club, please visit our website, www.press.org. That's *press.org*. I'd like to present our guest with the traditional National Press Club mug. I ask that you use it in your next movie, if at all possible.
[laughter/applause]

MR. YORK: [laughter] Thank you.

MR. BURR: My final question, sir – and we're pretty much out of time – if you were reincarnated as your character from *Logan's Run*, would it be as the character from *Logan's Run*. Basil Exposition, your character from *Austin Powers*? From *The Three Musketeers*? What character?

MR. YORK: Oh, behave, as Basil used to say. [laughter] No, I think we all like doing something new. It's nice to go back, but creating new frontiers and possibilities, I think that's always so interesting.

But I would like to thank you for this wonderful present. I really mean it. I'm so honored to be here. And thank you for attention, thank you C-SPAN. And get the word out about amyloidosis. Thank you for having me. It's a great honor to stand at this podium. Not undertaken lightly. And I shall never forget it. Thank you. [applause]

MR. BURR: Thank you, sir.

[applause]

END