JUNE 2002 SPECIAL EDITION

MYELOMA TODAY

A PUBLICATION OF THE INTERNATIONAL MYELOMA FOUNDATION

DEAR READER

Dear Reader,

This "Special Edition" of Myeloma Today is indeed special on a number of levels. What took place in Washington, D.C. the week of June 3rd was special not only for our myeloma community but also for our cancer community as a whole. The IMF, along with 40 other cancer organizations, all of whom belong to One Voice Against Cancer, (OVAC), came together as a unified force to convey one important message to Congress – to "fully fund the National Cancer Institute's bypass budget" and other critical programs at the National Institutes Of Health and the Centers for Disease Control and Prevention.

As a single unit, we climbed Capitol Hill. We were no longer playing the body parts war, no longer saying one cancer – my cancer – is more important than another. We stayed on point and delivered our message – to significantly increase the level of funding for cancer research – period. We know that "all boats will rise with the tide."

The IMF's lobbyist ,Tom Sheridan, made an important point when he said, "If we all want a piece of the pie, than we better bake a bigger pie!" It's everyone's responsibility to put pressure on our legislators to fully fund the bypass budget because that will enable us to bake a huge pie!

I had been asked to represent OVAC and testify before the Senate Health and Human Services Appropriations subcommittee Chaired by Senator Tom Harkin. A huge responsibility indeed. I truly felt like Mrs. Smith goes to Washington. I agonized about what I would say, how I could best present our message, our cause. All the usual questions raced through my mind, "Was I the best choice?" "Would I be able to deliver a strong enough message?" "Would I be too nervous or too emotional, would my hands and voice betray me?" "Could I deliver in only 5 minutes?"

The morning of the hearing, I was invited to attend a coffee meeting in Senator Harkin's office along with the delegates from Iowa and some of the other people who were to testify. It was a very heady morning, meeting the Senator, and when Secretary of

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IMF PRESIDENT SUSIE NOVIS TESTIFIES BEFORE SENATE APPROPRIATIONS SUBCOMMITTEE

Susie Novis testified on June 4, 2002, before the Senate Appropriations Subcom-mittee on Labor, Health, and Human Services, and Education. She represented the One Voice Against Cancer (OVAC) coalition to request funding for the National Institutes of Health (NIH), the National Cancer Institute's (NCI) Bypass Budget, and the Centers for Disease Control and Prevention (CDC) cancer programs.

Her testimony emphasized that success in the appropriations process is the only way to realize more funding for new myeloma and other cancer research programs. (*Please see page 4 for text of testimony*.)

Sen. Tom Harkin (D-IA) and Sen. Arlen Specter (R-PA) chaired the hearing on cancer research and prevention highlighting the need to fulfill the last year of a five-year pledge to double funding for NIH and raise awareness about the NCI Bypass Budget.

Sen. Harkin noted that defense research spending in the two years prior to beginning the process of doubling the NIH budget (1997-98) exceeded the cumulative federal spending for medical research for the entire 20th century. Sen. Specter set the tone by asking, “What's next for the NIH budget after we double it?” and answering himself with an emphatic, “I say triple it!"

Secretary of Health and Human Services Tommy Thompson, whose wife is a

> ***“IMF President Susie Novis' congressional testimony and NCI Director Andrew von Eschenbach's speech to the IMF Patient-Family Seminar highlighted a memorable first week of June for the myeloma and cancer communities in Washington DC.”***

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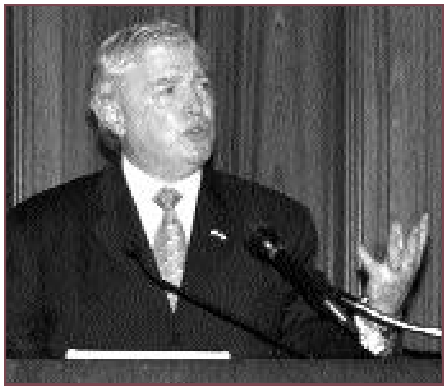
NCI DIRECTOR ANDREW VON ESCHENBACH'S SPEECH HIGHLIGHTS PATIENT-FAMILY SEMINAR

NCI Director Dr. Andrew von Eschenbach spoke to the attendees of the IMF Patient-Family Seminar on the evening of June 7, 2002, at Tysons Corner, VA. He highlighted his vision of the future of cancer research and how it relates to myeloma patients.

We have reached, according to Dr. von Eschenbach, a strategic inflection point; an opportunity that rarely occurs in the ongoing history of science. ■

(Please see page 5 for an excerpt from Dr. von Eschenbach's speech.)



The IMF is dedicated to improving the quality of life of myeloma patients while working toward prevention and a cure.

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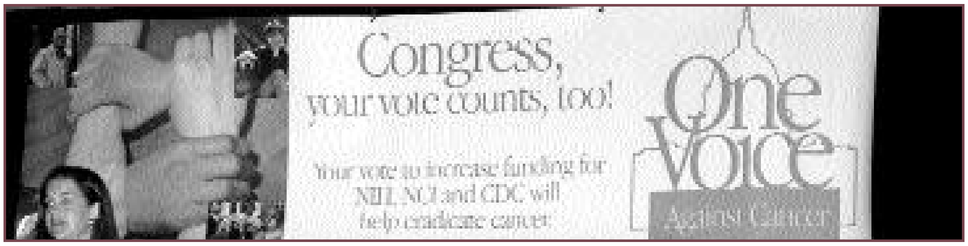

THE CANCER LANDSCAPE

IMF advocacy consultant Greg Brozeit conducted a session on One Voice Against Cancer Advocacy Day to provide an overview of OVAC priorities and how they fit into the overall picture of cancer research and advocacy.

By Greg Brozeit

I have often wondered why—when 1.2 million persons are diagnosed and another 500,000 die each year of cancer in this nation—cancer advocates do not muster more voices in support of research, especially compared to many of the political issues that gain attention. And then it hit me: we choose the political issues that interest us. Cancer chooses us.

Getting cancer is not a political act. But if we are serious about finding a cure for the various cancers that afflict us, we must be political. We must be political because it is through federal funding that we will accelerate research funding in meaningful amounts. And One Voice Against Cancer (OVAC) is the only broad-based cancer research funding coalition that articulates the needs of the entire cancer community.

Senator Harkin, Chair of the Senate Subcommittee

As we all learned in our civics classes, Congress can *authorize* anything it wants – and it usually does, to give the illusion that something is being done. *Appropriations* – funds released to be spent – are action. If it ain't appropriated, it ain't going to happen.

It is important to remember that Congress does not appropriate funds for specific medical research programs, projects, specific diseases, or cancers. Instead, Congress appropriates lump sums of annual funding to the NIH and its respective institutes, including NCI, and gives their directors the discretion to exercise their judgment based on scientific opportunity.

In my view, there are two obstacles that cause confusion and frustration among cancer research advocates.

OBSTACLE 1: The Arrogance of Diagnosis

Unfortunately, there exists a mindset among certain advocates that some cancers deserve more research than others. I call this attitude the arrogance of diagnosis. It is characterized, in my view, by a myopic, disease-centric view of the political world and seems to be most strongly held by individuals who are personally affected by a particular disease or type of cancer.

Cancer advocates who believe their form of the disease—or their affiliated organization's story about the disease—is more important than others are particularly prone to this attitude. So rather than educate themselves about issues like the Bypass Budget and the consistent gap between it and the actual federal funding levels for cancer research, they try to advocate for more research funding for **their** cancer alone.

The best argument against the arrogance of diagnosis is the OVAC agenda. The alternative is a continued politicization of the cancer appropriations process.

OBSTACLE 2: Silos

Gov. Roy Barnes (D-GA) articulated the second great obstacle at the May 2001 National Dialogue on Cancer meeting. According to Gov. Barnes, when dealing with the cancer community, he has to overcome what he calls "silos" when trying to implement cancer policy. He defined silos as the funding and policy advantages that each cancer group seeks to gain for its constituency.

As each group works to build its own silo, growth in one often comes at the expense of another. Or at least that is the perception by some. The more we become vested in building our particular silos, the less we get accomplished. At the federal

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OVAC ADVOCACY DAY

The Senate hearing was the high point of the One Voice Against Cancer Advocacy Day on June 4, 2002. More than 250 advocates from 44 states representing all cancers gathered on June 3 for an education and training day. Dan Smith and Wendy Selig of the American Cancer Society introduced the goals and history of OVAC. Following an introduction by the founder and president of the Pancreatic Cancer Action Network, Paula Kim, the advocates were given a moving speech from pancreatic cancer patient Kim Duhart of Ft. Washington, MD.

After the opening session, the advocates attended training sessions, including the Basics of Grassroots Advocacy, Keeping the Grassroots Growing, and a primer on the CDC cancer programs.

Greg Brozeit of the IMF conducted a session on The Cancer Landscape, which explained the OVAC agenda and its context within the world of cancer research advocacy.

All then attended the June 4th hearing in the U.S. Senate and spent the remainder of the day making visits with their senators and members of Congress to advocate for the OVAC funding agenda. ■

Daniel Smith, OVAC founder.

WHAT IS THE BYPASS BUDGET?

The NCI Director's Bypass Budget is NCI's annual funding request. Unlike other budget requests, the Bypass Budget is submitted directly to the President for consideration before the drafting of the annual budget submitted to Congress. This process was authorized under the National Cancer Act to bypass the normal procedures of submitting budget proposals through the NIH director and the Secretary of HHS. The Bypass Budget identifies NCI goals and the required levels of funding needed to meet those goals. In the 30-plus years of the Bypass Budget process, actual funding approved and signed into law *for NCI has never matched the Bypass Budget proposal*.

THE IMF GOES TO WASHINGTON

By The Unknown Patient

The Unknown Patient has done his share of traveling for the IMF. This June, it was time to pack the Unknown bags again and haul the Unknown bones onto the USAir Shuttle to Washington, DC. Your Unknown friend agreed to accompany IMFer Mike Katz for a week to include the One Voice Against Cancer (OVAC) Advocacy Day, a Senate hearing on cancer research funding, meetings at the National Cancer Institute (NCI), the IMF Patient & Family Tysons Corner Seminar, and the Eastern Cooperative Oncology Group clinical trials meeting. How Mike got mixed up in so many things remains Unknown.

First on the agenda was the OVAC advocacy training sessions. The sessions were intended to prepare us for lobbying activities planned for the next day, to coincide with the Senate Appropriations Committee hearing. Attendees included advocates from across the US, representing over forty different advocacy organizations and a wide variety of cancers. The training focused on understanding the government institutions and programs that deal with cancer research, the congressional allocations process, lobbying and advocacy. The sessions offered some really good information to help us all understand what we were asking for and how to ask for it. It also provided a great opportunity to meet so many committed advocates and compare notes.

After the training sessions, we regrouped by state and discussed who was going to be attending each of the lobbying sessions with Senate and House members and who would play what role at each session. When meeting with members of Congress or their staff, our job is to explain why we're there, as constituents and cancer advocates. We then have the opportunity to talk about the importance of cancer research, personalize it by sharing our own stories, and then deliver the "ask." The "ask" outlines specific appropriations for the NCI, the National Institutes Of Health (NIH), the National Center for Minority Health and Health Disparities, and the Centers For Disease Control (CDC), to fund cancer prevention, treatment, and research that we would like to be included in this year's appropriations.

The next morning we set out, *en masse*, for Capitol Hill to attend the Senate Appropriations hearing, chaired by Iowa Democratic Senator Tom Harkin, assisted by ranking Pennsylvania Republican Senator Arlen Specter. These senators are both cancer survivors, and are passionate about cancer research.

Mike and I were a bit winded and more than moist after hustling to get to the Hill in time to get good seats for the hearing. IMF President Susie Novis was chosen to represent OVAC on the witness panel, so we were pretty excited and wanted to make sure we could be there to see it live and in person.

The Senate Appropriations Subcommittee on Labor, HHS, Education, and Related Agencies hearing began with testimony by HHS Secretary Tommy Thompson. He focused on activities at the NCI and the NIH, which include major investments in cancer research, especially for prevention and treatment. Senator Harkin then called the witness panel, which included:

- Elmer Huerta, Cancer Preventorium, Washington Hospital Center
- Ronald Herberman, Director, University of Pittsburgh Cancer Institute
- Susie Novis, President/Founder, IMF
- Michael Bruene, Brain Cancer Survivor
- Steve Case, Chairman, AOL Time Warner

Dr. Huerta, a prominent physician and radio personality, was the first to speak. Dr. Huerta's testimony focused on cancer prevention and on treating the whole person and not just the cancer. He was followed by Dr. Ronald Herberman, a cancer researcher, who spoke about the progress that has been made and the promise of new technologies and new directions in cancer research.

IMF President Susie Novis was next, representing OVAC. Susie's testimony (*please see page 2*) laid out a logical case for increased funding but also personalized the need by sharing how myeloma altered her life. She also introduced myeloma patient Mary Godwin, a nurse from Cedar Rapids, Iowa, and her daughter Lanissa. Susie noted that Brad High, a patient from Pennsylvania, was to attend but lost his battle with myeloma just a few weeks before the hearing. Susie finished her testimony by reminding the assembled crowd that everyone in the room has been affected by cancer and that we cannot afford not to fund the research necessary to end the suffering. When she was done, the room burst into applause, led by Senator Harkin who gave her a big "thumbs up," and thanked her for a "powerful statement." Way to go Susie!

Brain cancer survivor Michael Bruene gave an emotional statement, personalizing the horror of cancer and the special challenges of dealing with incurable disease. He was followed by AOL Time Warner Chairman, Steve Case, whose brother Daniel was fighting brain cancer. (*Daniel passed away at age 44, four weeks after the hearing.)*

At the conclusion of the hear-

Please see Unknown Patient, page 6

TESTIMONY OF SUSIE NOVIS BEFORE THE SENATE APPROPRIATIONS SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES, EDUCATION AND RELATED AGENCIES

AOL-Time Warner's Steve Case with IMF President Susie Novis

Mr. Chairman, I'm Susie Novis, President of the International Myeloma Foundation, the oldest and largest nonprofit serving the multiple myeloma community.

Multiple myeloma is an incurable cancer of bone marrow plasma cells. Myeloma patients represent 1% of all cancer diagnoses and 2% of the cancer mortality in the U.S.

Myeloma patients experience painful bone fractures, particularly in the vertebrae, ribs, and hips. Additional complications include kidney failure, anemia, and infections that ultimately lead to death.

I am here representing not just the multiple myeloma community, but all cancers represented by One Voice Against Cancer. One Voice is a coalition of more than 40 national and community-based organizations that represent tens of millions of Americans. One Voice was formed to unify the public health community on the need for a comprehensive, targeted federal approach to develop cures for the spectrum of cancers affecting our nation.

On behalf of One Voice, I would like to ask this Committee to fulfill the following appropriations requests for fiscal year 2003:

- $27.3 billion for National Institutes of Health to fulfill the 5-year doubling pledge;
- $5.69 billion for the National cancer Institute to fulfill the NCI Director's Bypass Budget recommendation:
- $199.6 million for the National Center for Minority Health and Health Disparities to lower the disproportionate rate of cancer incidence and mortality among undeserved communities; and
- $348 million for the Centers for Disease Control and Prevention for its cancer programs to enhance education, outreach, prevention and screening.

We are particularly supportive of the idea that Congress fully fund the NCI Director's Bypass Budget.

Fully funding the Bypass Budget will provide hope to those Americans who will be diagnosed with rare, deadly forms of cancer - which include myeloma, kidney, and pancreatic cancer. The 5-year survival rates range from 4% for pancreatic cancer to 28% for myeloma. Without dramatic increases in research funding, the outlook for these patients will remain bleak.

Fulfilling the Bypass Budget will provided resources for new research for cancers that have been traditionally underfunded by NCI allowing NCI Director Andrew von Eschenbach to implement the New Paradigm for cancer research. This approach will lead to targeted therapies that treat cancer at the molecular level. This molecular approach is indeed the ultimate expression of "a rising tide lifting all boats."

Today is a very emotional day for me. It's my anniversary. Thirteen years ago today, Brian Novis and I were married. Brian was diagnosed with multiple myeloma when he went for a blood test in preparation for our marriage. Brian was only 33 years old.

His doctor told him he had 3 to 5 years to live. We prayed that he doctors were wrong, that we would be able to raise a family and have a long and happy life together. Brian died in 1992, just 4 years after his diagnosis. But even though we never had children we did create a family, with the help of Dr. Brian Durie – the International Myeloma Foundation: a family comprised of patients, caregivers, and professionals. I would like to introduce you to two members of our family.

Mary Godwin is a nurse from Cedar Rapids, Iowa who was diagnosed with myeloma in 1996 after injuring her back while lifting a patient preparing for surgery. Mary's husband of 20 years runs a family-owned restaurant. Her 14-years-old daughter Lanissa has spent almost half her life knowing that her mother is fighting a rare, debilitating cancer. But as Mary said to me, she "just needs to keep on going, the other choices aren't so good."

Brad High of Haverford, Pennsylvania believed strongly in One Voice Against Cancer. He understood the need for cancer advocates to work together and avoid the inclination to say that one cancer is more important than another. Brad planned to be here today but he lost his seven-year battle with myeloma on May 22nd.

Everyone in this room has been touched by cancer. I lost my husband to myeloma, my mother to colon cancer, and I have lost many dear friends to cancer. You know as well as anyone, Mr. Chairman, cancer destroys not just the person – it destroys the family, it destroys the community.

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EXCERPTS FROM DR. VON ESCHENBACH'S ADDRESS: "DIRECTION OF NCI"

Good evening. Just for a few minutes, I want to depart from my prepared remarks. The night before the Senate hearing, I was briefing the Secretary for his presentation on the panel that immediately preceded Susie's. I knew who was going to be on the second panel, and I was wondering, "Who is this Susie?" Well, now I know!

I don't think I fully appreciated why I was coming here until a few minutes ago. What I've learned in the last hour or so is how important it is for you to talk to me. How important it is for me to see your passion, your commitment, your resolve, your pain. How important it is for me to be reminded of why I am privileged to be the director of the National Cancer Institute. I've been privileged in a variety of ways throughout my career, but I have also been privileged to understand and "walk the walk," as I am also a two-time cancer survivor. We're in this together.

I want to share with you a message of new hope and renewed hope that there is within our grasp an opportunity to truly, fundamentally change the face of cancer. I want to share with you a concept that I refer to as "strategic inflection." This issue of strategic inflection has implications specifically for multiple myeloma, and, as you'll see, is a paradigm for the entire arena of cancer. There are enormous possibilities, and the realization is only going to come about through partnerships.

We are beginning to be able to understand cancer at its basic biomedical and biological level. We have arrived in biology at that strategic inflection. I borrow that term from Andy Grove, who in his book Only the Paranoid Survive, refers to it as an event when change is absolutely profound; what he calls a 10X change.

NEXT STEPS

As Congress makes its way through a slew of appropriations bill, the Labor, Health and Human Services and Education appropriations will most likely see a vote in September. The Congressional recess spans the month of August – that gives us an opportunity to write, call and meet with Members of Congress in our districts.

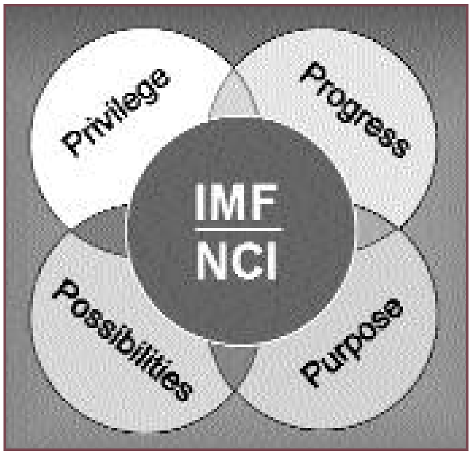
It is imperative that members of the IMF make their voices heard, particularly in a budget cycle where competing national priorities (including homeland security) will be thrown into the mix. The advocacy team will remain hard at work throughout the summer months, preparing to do battle on behalf of the myeloma community.

In his own particular area he gave this example: the introduction of the microprocessor. Those who understood its implications rode the expediential curve and the others went into decline. We are at a strategic inflection in oncology. If you think back to the turn of the 20th century, the fundamental quest of science was to understand the nature of matter. Physics was the queen of sciences. Our focus was on the atom and unlocking the secrets of the nucleus. When we accomplished that, we created a strategic inflection that changed the course of civilization. Almost eradicated civilization—but fundamentally changed it.

At the turn of the 21st century, almost one hundred years later, our focus in science has changed from understanding the nature of matter to understanding the fundamental nature of life. We have shifted from physics to biology, molecular biology and genetics. Instead of unleashing the secrets of the nucleus of the atom, we are unraveling the secrets of the nucleus of the living cell. This has placed biology at the point of strategic inflection.

The funding Susie was pleading for in her address to Congress is an investment that could change not only our ability to deal with cancer, but with a whole host of diseases in which there are degenerative changes. For the first time, we have begun to understand cancer at the genetic, molecular, and cellular level. This has begun to create a whole shift in our approach to cancer. Today the transition is away from "seek and destroy" to the phenomenon of target control. We now understand the mechanisms that result in a normal cell becoming a malignant cancer cell.

The other thing that is apparent to us is that this process of malignant progression involves very discreet steps that are biologically controlled. In order for a cancer cell to succeed in its mission, it has to be able to effectively compete in a variety of events—growth, invasion, metastasis, resistance to therapy. We can begin to think of not necessarily having to destroy the cancer but of controlling it and preventing it from being able to succeed in any one of those steps along the way. We begin to see, in this new paradigm, that cancer can be quite vulnerable because there are multiple places where we can successfully intervene and stop, impede, or impair its progress.



Dr. von Eschenbach's slide of his vision for the partnership between IMF and the NCI.

We have gained ground on cancer, but it's clear that we have not even begun to scratch the surface in terms of what we must achieve. You know this from the perspective of myeloma and the tragedy that this disease carries with it. Our challenge is great, but our possibilities are even greater. Our paradigm of the past was to see the tip of the iceberg and use our traditional weapons—surgery, chemotherapy, and radiation—to try to destroy it. Now we can look below the surface and see the fundamental processes that are giving rise to the cancer and attack them individually and collectively. All this is coming at almost breakneck speed because of our incredible evolving knowledge and the advances in technology.

One of the obvious advances that has occurred in multiple myeloma is the recognition of the important role of growth factors. One of the most important drugs that has occurred in treatment—in blocking of angiogenesis, or the development of abnormal endothelial cells and blood vessels—is thalidomide. This has had obvious benefit in multiple tumors, particularly in myeloma. The other very important breakthrough is our understanding of the role that NF Kappa B plays as an accelerator in the malignant process. A drug has been developed that is a proteasome inhibitor, PS341. Using it, myeloma cells appropriately undergo programmed cell death or apoptosis.

Once the mechanism was understood, these biologic-based interventions became available as effective modalities of treatment. We need to promote and exploit, through research, our understanding of these mechanisms. Cancer is an extraordinarily complex problem. We have only begun to scratch the surface in our understanding of its underlying biology, but these breakthroughs have provided us with new opportunities, and

Please see Dr. von Eschenbach, page 7

Landscape – continued

level, one way it translates is in the comprehensive manner in which the Bypass Budget is ignored by policymakers and advocates.

The mentality behind silo-building helps to make cancer advocates their own worst enemies. Far too often, individual disease advocates become mired in the minutia of their own limited agendas at the expense of bigger ideas. But if they achieved the bigger ideas, each of their constituencies would have benefited more than under the status quo. This helps policy makers ignore comprehensive issues like the Bypass Budget. And it explains why so few in the community will talk the talk about the Bypass Budget.

THINK BIG

Achievement of the OVAC agenda would allow all in the cancer community to think big; to realistically dream of what could be. It would allow cancer researchers to focus more on translating research about molecularly targeted therapies into drugs and therapies that benefit all cancer patients. Such programs could explore research initiatives in the smaller, deadlier cancers that have few market incentives to develop new drugs and therapies.

Senators Cochran, staffer Bettilou Taylor, Senator Specter, Senator Harkin responding to OVAC testimony

The key to creating a pool of significant federal funding for cancer research, and especially for the deadliest cancers, will be found, in my view, in the willingness of their representative advocacy groups to ally with each other and promote agendas for other cancers with similar experiences.

We cancer advocates should learn from the lessons that those involved in the rescues and recoveries of September 11th taught us. We should learn that if we all step back, take in the scenery, speak with one voice, and look each other honestly in the eyes, we can find common ground and build something of beauty that we can be proud of. We can conquer cancer. But we cannot let selfishly built silos get in the way of our real mission. That is why we must speak with One Voice Against Cancer. ■

Note: For a copy of the full text, contact Greg Brozeit at *greg.brozeit@worldnet.att.net*

UNKNOWN PATIENT – continued

ing, Senator Harkin asked if anyone had any additional comments they wanted to make. Susie Novis jumped in, reiterating the need to fully fund the NCI bypass budget and observing that over 70% of approved NCI grants cannot be funded. This set off a flurry of dialog on how big a difference the doubling of the budget had made, capping the hearing with a bit of excitement and making it clear that there were significant challenges ahead but much promise for a brighter future.

Friday was a busy day for Mike and his Unknown escort. First stop, the NCI, for a meeting with the Director, Dr. Andrew Von Eschenbach. Mike and fellow members of the NCI Director's Consumer Liaison Group (DCLG) were set to discuss the future role and priorities for the group with the Director and his staff. Dr. Von Eschenbach was very interested in our views but also spent considerable time talking about his ideas, soliciting feedback, and facilitating a very animated, interactive discussion. Dr. Von Eschenbach is a very intelligent man who clearly cares about cancer patients and their issues. His appointment bodes well for the future.

From there, your Unknown friend dashed to the NCI Clinical Center. IMFer Norma Holmes had arranged for a tour of the Clinical Center, which is where the NCI conducts cancer clinical trials and performs much of its "intramural research" – the NCI's internal research effort, conducted by NCI scientists. A number of NCI research scientists presented promising new projects that could yield results for myeloma patients within the next few years. The approaches being discussed are truly novel, making use of the most recent advances in molecular biology and targeted therapy.

From there, we hitched a ride to Tyson's Corner with IMF advocacy consultant Greg Brozeit. We joined the IMF crowd for the welcome reception and dinner that preceded the Patient & Family Seminar. We were joined by NCI Director Andrew Von Eschenbach, who took time out of his busy schedule (yes, there are people even busier than the Unknown Patient!) to join us and share his views on future directions in cancer research and specifically, how myeloma research will be impacted. The Unknown Patient was especially pleased that Dr. Von Eschenbach thanked the IMF and its members for putting a face on myeloma and the need for further research.

We were also fortunate to have with us Drs. Kyle, Greipp, and Rajkumar of the Mayo Clinic, as well as Dr. Jagannath of New York's St. Vincent's Comprehensive Cancer Center. And, it was great to see so many old and new friends, myeloma patients and family members, enjoying each other's company and sharing experiences.

The next morning began bright and early with the IMF seminar. The seminar began with Carol Svec, patient advocate, speaking about how to be an "active patient." Carol was followed by our own Mike Katz, who spoke about how to get organized and keep track of your medical records and test results. They were followed by Drs. Kyle, Durie, Rajkumar, Jagannath, and Coumans, who covered a broad range of myeloma-related topics. The breaks were a wonderful opportunity to compare notes and make new friends. The Unknown Patient missed most of the breakout sessions, ducking out with Mike Katz, who was speaking about clinical trials at the ECOG meeting in DC. After Mike's talk, it was back to Tysons Corner for the conclusion of the IMF seminar, which found the attendees energized and hopeful. The Unknown Patient has been to almost all of the IMF's seminars and never ceases to be amazed how there always seems to be something new and so many wonderful new people at each session.

The week ended on Sunday, as the Unknown Patient tailed Mike Katz at the ECOG meeting. Sunday's program included a meeting of the ECOG myeloma committee, which is responsible for developing and managing large-scale, national clinical trials for multiple myeloma. Mike also attended a meeting of ECOG's Underserved Committee, chaired by IMF board member Dr. Edith Mitchell, which addresses issues of how to make clinical trials more accessible to members of underserved populations. The day ended with a plenary session at which Mayo Clinic myeloma specialist Dr. Rafael Fonseca received two awards, the ECOG Young Investigator Award and an award for an Outsanding Research Project. ECOG chair Dr. Bob Comis characterized Dr. Fonseca as a "young researcher taking the Group by storm." Great to have talented young people like Rafael joining the ranks of scientists battling myeloma!

After the plenary session, the Unknown Patient followed Mike to a reception, after which we made a bee line for the airport, grabbing the last Shuttle back to New York for a well-deserved, albeit short rest. ■

DEAR READER – *continued*

HHS, Tommy Thompson, walked in, the buzz in the room increased greatly. Finally, the moment came and we were ushered into the Senate hearing room, through a back door. My first impression was that the room was very crowded and the lights were really bright. As we quickly took our seats I was glad to see familiar faces. Sitting right up front were fellow IMF Board members Mike Katz and Rich Saletan, and my step-daughter Annabel.

The first person called upon to testify was Secretary Thompson. Immediately following his testimony, I knew the moment had arrived. Our panel was asked to come forward and take their seats. I took a deep breath, said a silent prayer, and joined Dr. Huerta , Dr. Heberman, brain cancer patient Mike Bruene, and Steve Case, Chairman and CEO of AOL Time Warner, at the table.

In turn, we were each asked to present our testimony. When I finished, I felt a big surge of relief, and hoped that I was able to deliver. Then the room erupted in applause and Senator Harkin looked at me and said, “Very powerful, very powerful.”

I have to say that part of that day is still a bit of a blur. We immediately left the hearing room and headed to stops in what seemed like hundreds of congressional offices. It was an incredible day, made only more exciting by the dozens of e-mails I received from people around the country who had seen the C-SPAN coverage of the event.

I am sad to say that the recent weeks have seen the deaths of two well-known Americans from myeloma, J. Carter Brown, the former head of the National Gallery of Art in Washington, DC, and advice columnist Ann Landers.

For every step we take forward we are reminded of just how far we have yet to go. I’m asking all of you to please join this effort – together we can achieve our dream and find a cure for myeloma.

Susie Novis
President

NOVIS TESTIMONY – *continued*

It breaks hearts and it crushes dreams.

When Brian Novis decided to start the International Myeloma Foundation I was skeptical – but he looked at me and said "Susie, one person can make a difference, but two people can make a miracle." As I look around this room I see many people who can make miracles happen. Cancer can be cured. It’s going to take money and commitment to get the job done, especially for cancers like myeloma. Some of you may be thinking, “How can we afford to increase the funding for cancer research?” But I say, how can we afford not to?

We are One Voice Against Cancer – and our voices must be heard. ■

APPROPRIATIONS – *continued*

cancer survivor and whose mother died of melanoma, opened the hearing by expressing his own and the Administration's support for cancer research and prevention programs. In this year's proposed budget, President Bush called for $27.3 billion for NIH to complete the five-year doubling pledge, and for $5.1 billion for NCI.

Susie Novis was joined on her panel by Steve Case, chairman of AOL-Time Warner, Michael Bruene, a brain cancer patient from Des Moines, IA, Dr. Ronald Herberman from the University of Pittsburgh, and Dr. Elmer Huerta, Director of the Cancer Preventorium at Washington, D.C. Hospital.

Steve Case testified in support of more innovative private-public partnerships in cancer research using the new Case-supported ABC Foundation to support brain cancer research. Case's brother was diagnosed with brain cancer last year.

Michael Bruene testified about his personal experiences since being diagnosed with a brain tumor two years ago. Drs. Herberman and Huerta focused their remarks on new directions in cancer research and prevention. ■

DR. VON ESCHENBACH – *continued*

we need to make sure that the breakthroughs and the understanding continue.

Our delivery process, particularly through clinical trials, continues to be an important part of the NCI agenda. We must maintain a work force that can discover, create, and deliver. Our training programs will continue to be emphasized. We are also looking at promoting and developing alternative disciplines that are going to be necessary to drive this new paradigm—disciplines that have not normally been part of the traditional mainstream of biology-based interventions. The underlying drive is a strategy I would like to create over the next months, and that is the strategy of systems biology and seamless oncology.

Systems biology investigates each component of the mechanism, but recognizes that the cancer cell does not exist in a vacuum. It exists in a person, and that is as important to the equation as the cancer cell itself. We must begin to emphasize our understanding of the person with cancer in terms of host factors. There are a variety of host factors that enable or empower a patient to combat and cope with cancer that are poorly understood. With the cancer cell itself, we pay a great deal of attention to the genetic and molecular pathways and cell-cell interactions; with regard to the person, we understand a host of factors that have an impact on the outcome of the tumor, particularly the very important issues relating to survivorship. The interaction of the environment with individual host factors, as well as the ability to understand our impact on populations that are at risk, will be an extremely important part of the agenda. Seamless oncology means that we go from patient observation to the laboratory and back to the patient in a continuous process. This will allow us to see the effect of biologic interventions on patients and use that information to reinform our investigations, enabling us to keep the engine of discovery and delivery operational.

I don’t think you need to be a cancer survivor to be a dedicated researcher, but it sure gives you a sense of urgency. I share with you that sense of urgency. We have priorities that will have a specific impact on multiple myeloma. The idea of understanding genomic instability that gives rise to the evolution of tumors, gene-environmental interaction, stem cell research, and particularly important, the effect of public-private partnerships on the acceleration of drug development, are priorities for the NCI that will have a direct effect on multiple myeloma. There are a number of new projects underway at the NCI that will specifically benefit the areas of research that you are interested in and we will continue to develop and nurture those as well.

The NCI plays a critically important role in fostering and developing research. But the fact of the matter is, no matter how big our budget, the NCI cannot do it alone. My commitment is to collaboration and partnership. Discovery does not reach its full benefit until it actually results in the development of an intervention that can be applied to a patient and save a life. I believe we can seize the opportunity of recognizing how our privilege and our purpose are interconnected. There are extraordinary possibilities within our grasp, and if we can work collaboratively and cooperatively, we can make the dream of a world free of pain and suffering and death due to cancer a reality. We can do it in our time. One hundred years ago they unlocked the mysteries of the atom, and by doing so saved the world from a disaster that was war. We have the same opportunity to use our knowledge of the living cell to eliminate the diseases that result because of cell abnormalities. It is within our grasp to make that happen. Conquering cancer is a reality within our grasp, and it is now our time to seize that reality.

Thank you for the privilege of being with you tonight, and for the reminder of why I must do what I have been called to do, and how important it is to be of service to you. ■

WASHINGTON COMMENTS

Senator Specter

"The unique characteristic of OVAC that is so effective with policymakers is its ability to bring together the continuum of cancer advocacy groups around one, unified message -- that the federal government must maintain sustained increases for vital cancer research and application programs. We have harnessed the passion and the power of the cancer stories of millions of Americans and developed a potent vehicle for delivering our urgent, life-saving message to Congress." **Dan Smith, American Cancer Society**

"OVAC has been a valuable platform on which we can amplify our collective voices on the most critical issue to all of us….medical research funding to find a cure!" **George Dahlman, Leukemia & Lymphoma Society**

"Working with other organizations in OVAC shows the value of groups with common agendas working together. Everyone has a seat at the table, everyone has a voice in the decisions … and people touched by cancer are the ultimate beneficiaries of our collective, collaborative efforts. OVAC has helped new organizations have a real impact in DC. OVAC lets us learn from people with experience and knowledge, and has shortened our learning curve. The end result? We've become effective cancer advocates." **Nancy Roach, Colon Cancer Alliance, Seattle, WA**

"Al and I again attended OVAC this year. It was even more meaningful and rewarding this year, as we had just lost our dear leader and friend, Brad High, who fought so hard for so long. It was his intention to be there this year – he knew the importance of telling your personal story, along with over 40 other cancer groups, to ask our congressmen to support the bill for more funding. It obviously has much more significance when we do this as a large group. We're so glad we were able to be there." **Marilyn Alexander and Al Jacobsen, Philadelphia, PA**

"I am happy the IMF has joined forces with OVAC. There is strength in numbers. I feel our presence on Capitol Hill this lobby day was recognized and received differently than last year due to our focused message. Our requests were spelled out clearly for us and for the elected officials. While these visits are absolutely necessary it can not stop with a once-a-year trip to Washington D.C. The most important message I left with is we must continue to spread the word at home. Our cancer families are depending on us and our elected officials need to hear from us, often!" **Connie Whiteman, Modesto, CA**

"OVAC is a vital reminder to Congress that cancer is treatable, curable. OVAC's mission is not just about funding cancer, but moving relevant basic research to the lives of constituents. Every three days in America the equivalent of 9/11 deaths happen in cancer. OVAC is a crucial voice in keeping the nation's economic and medical priorities straight." **Norma Holmes, Arlington, VA**

"The OVAC lobbying effort in Washington, DC was like a breath of fresh air, particularly for those of us with orphan and deadly cancers. The concept of raising appropriations up to the levels of what is authorized in NCI budgets will stop a whole bunch of winner / loser infighting over the precious dollars that can lead to lives saved for cancers who right now see very little federal funding. I think we were well prepared; we were heard; and Susie Novis was marvelous." **Tim Scully, Rancho Palos Verdes, CA**

"Incredible experience! An event to look forward to! As a first-timer, I had no idea what to expect; however, the interactions with other Cancer advocates and the feeling of making a difference, was an unforgettable emotion." **David Robertson, Bowling Green, Kentucky**

"When dealing with my diagnosis of multiple myeloma, initially my wife and I felt helpless. As we sat in on the OVAC meeting, surrounded in the audience and on the panel by so may brave, strong and determined people, we had such a feeling of empowerment. What a great concept, so many people dealing with many different types of cancer coming together to raise their voices as one. I am convinced that every time I attend a meeting such as OVAC, or a seminar on cancer, that a cure for all is no longer down a long and winding road, but just around the corner." **Douglas Milke, Philadelphia, PA**

Senator Harkin and Mary Godwin

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