

**FEDERALLY FUNDED CANCER RESEARCH:  
COORDINATION AND INNOVATION**

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**HEARING**

BEFORE THE

**COMMITTEE ON OVERSIGHT  
AND GOVERNMENT REFORM  
HOUSE OF REPRESENTATIVES**

ONE HUNDRED FIFTEENTH CONGRESS

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## **FEDERALLY FUNDED CANCER RESEARCH: COORDINATION AND INNOVATION**

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**Wednesday, March 29, 2017**

HOUSE OF REPRESENTATIVES,  
COMMITTEE ON OVERSIGHT AND GOVERNMENT REFORM,  
*Washington, D.C.*

The committee met, pursuant to call, at 9:30 a.m., in Room 2154, Rayburn House Office Building, Hon. Jason Chaffetz [chairman of the committee] presiding.

Present: Representatives Chaffetz, Duncan, Jordan, Amash, Foxx, DeSantis, Ross, Walker, Blum, Hice, Grothman, Hurd, Mitchell, Cummings, Connolly, Kelly, Lawrence, Watson Coleman, Demings, Krishnamoorthi, Raskin, Welch, and DeSaulnier.

Also Present: Representative Dingell.

Chairman CHAFFETZ. The Committee on Oversight and Government Reform will come to order.

And, without objection, the chair is authorized to declare a recess at any time.

We have a very important hearing this morning on federally funded cancer research, coordination, and innovation. And this one is—some hearings are more important than others. I wish it was the type of hearing that was on the headline, top of the fold of every newspaper that we have. But it is—cancer is something that statistically is going to touch every family in some way, shape, or form.

And unfortunately, I've had that personal experience myself. I lost my mom to breast cancer. She fought it for some 10-plus years. Passed away in 1995. My dad, who was old school, my dad was the kind of guy who never thought he had to have a checkup; he'd be just fine. He felt fine; he didn't need a checkup. Unfortunately, he got colon cancer, and doctors at least told me that if he had had any sort of checkup in the 8 or 10 years preceding that, that he would probably still be here with us today. He passed away a few years ago, and I miss him. I miss them both.

And having to go through that is not something you wish upon anybody. In my own life, there are a lot of blessings that came with that, a lot of things that allowed me to get closer to my parents and have amazing experience with my parents. Without getting too personal about that, I think the importance here in the discussion that we're going to have, it's amazing to me: cancer will take the life of roughly 1,500 people a day—1,500 people a day.

So believe me: I'm a strong advocate for the United States military. I champion more money for the United States military. I want the men and women to have the most resources to protect and de-

fend this Nation. But let's put in perspective that 1,500 people a day are going to die from cancer. And so, if you look at the trillions of dollars our government will spend, why is fighting cancer not a much, much higher priority? It is for me. I think it is for a lot of people.

I hated the President's budget. I got a lot of respect for Mick Mulvaney and President Trump himself, but I thought his budget proposal on this category was pathetic and inadequate. We should be spending billions of dollars to solve this.

So part of—the heart of what we want to hear is, how much does the money make the difference? What could we do if we did have the resources? And with the resources we are throwing at it, which is a handful, billions—again, I don't want to treat it lightly—but compared to the \$4 trillion we will spend this year, we are going to spend a couple billion fighting what is going to ultimately kill 1,500 people a day, that equation to me just doesn't make sense. We want to hear not only what could happen if there was more funding, what is happening with the funding that is going on, and what are some of the exciting developments? Every once in a while, there will be a story on the news or in the newspaper and everybody gets some hope. I can certainly tell that there has been huge progress since, for instance, my mom was fighting this in the 1980s.

My wife, Julie, she works for a plastic surgeon in Utah. She got her degree in psychology, and she is working with women who are fighting breast cancer. And it's very satisfying, and I'm very proud of her and the great, important work that she does there. But sure enough, every day, day in and day out, young women are coming in and fighting this horrific disease. They didn't ever think they were going to get it, and now they're fighting it. And there are some really exciting, amazing things that I think give people a lot of hope, a lot of reason to cheer and to be excited, even though they're having to go through one of—if not the most—difficult and horrific things in their lives.

We have cancers of various types. And I'm glad we have Mrs. Carr here, who is going to tell a personal story, and I know it's hard for a family to talk about their own experience, but I think it's good to hear from the family, but it's also good to hear for some of the most exciting developments from some of the most prestigious institutions across this country. And we could fill weeks on end of hearings talking about people's stories. So we're going to have a host of hearings, and we're going to watch all these news stations. And they're going to talk about this, that, and the other. And the thing that's probably going to affect real lives more than anything else is going to be this topic in this hearing. And I do wish it would get the highlight and the headlines that it deserves. And I do wish there was more of a national imperative.

And I think if it's one of those unique things that if actually we went house by house, home by home, voter by voter, and asked them, "Where do you want to spend money, where should we prioritize money," this would be at the top of that list.

Look, I'm a really conservative person, but when you spend—or when you have 1,500 people a day dying, this is not just, you know, "Hey, we got to push this down to a local budget"; this should be

the national imperative that drives us all to fund it properly and to truly, truly make a difference. That's why I wanted to call the hearing today, and I think we all feel that way.

I've gone over my time. Let me yield back and now recognize the ranking member, Mr. Cummings.

[Prepared statement of Chairman Chaffetz follows:]

Mr. CUMMINGS. Thank you very much, Mr. Chairman, for calling this very important hearing today, and it is very important. I thank all of our witnesses for being here to share your insight with us, especially you, Mrs. Carr, and your family. I'm so glad that you're here with your family to share the story of your son Chad's amazing bravery in his battle against cancer.

Today, the single biggest danger we face in fighting cancer and other deadly diseases in this country is President Trump's budget. Earlier this month, President Trump proposed a budget that would decimate the budget of the National Institutes of Health. It would slash funding next year by nearly \$6 billion or about a fifth of NIH's budget. It is not going to be enough for us to complain. We have got to turn that around. His proposal gives little explanation for targeting NIH for this massive cut, which can only be described as heartless.

After he issued his budget, the White House Press Secretary, Sean Spicer, tried to explain that these cuts were not really cuts at all. He was asked about the NIH budget, and he argued that only in Washington does less funding mean there was a cut. Here is what he said, and I quote: "There is this assumption in Washington that if you get less money, it's a cut. And I think that the reality is that, in a lot of these, there's efficiencies, duplicity, ways to spend money better. And I think if you're wasting a lot of money, that's not a true dollar spent."

I wish he could talk to a few of the people that I know who, years ago, went to NIH with what was described as a fatal disease and in a matter of a few years, because of research, because some very smart and imaginative people, people who dared to dream bigger dreams, who had bigger hopes, they were able to turn, Mrs. Carr, a fatal disease type of cancer, into a chronic. And I know of people like that. That's what Mr. Spicer, he may not get that. And only when you're going through it, your family is going through it, maybe that's what it takes for people to fully comprehend how significant taking that percentage of money from an NIH budget from institutions all over the country doing significant research.

So I know, Mrs. Carr, that in your written testimony for today, you said President Trump's budget cut, and I quote, "hits me right in the gut." Well, you're not alone. There's a bipartisan outrage—and I think you heard the chairman say this—over this proposal to slash the NIH funding.

On March 17, Republican Congressman Tom Cole said this, and I quote: "I don't favor cutting NIH or Centers for Disease Control. You're much more likely to die in a pandemic than a terrorist attack, and so that's part of the defense of the country as well," end of quote.

Mrs. Carr, in your testimony, which I hope every Member of Congress reads, you point out that we need to devote more funding to this critical research, not less, and we need to make sure it is di-

rected to cases like your son's, which have little or no Federal funding devoted to them today. Mr. Spicer did not make his quote, "less funding is not a cut" argument, when the President proposed increasing the Pentagon budget by \$54 billion next year alone.

Our committee had a hearing last week, just last week, on how the Defense Department is wasting tens of billions of dollars, but for some reason, cancer research is decimated rather than trimming the bloated defense budget. I believe that there are few investments more significant than the investments we make in biomedical research. The work of NIH is transformational with the power to turn ideas into cures, the idea that there's a possibility that there is a cure over here, and we just cannot reach it. We are reaching for it, but we cannot reach it. We're trying to get it, but we cannot reach it. And we know that if we could just get it, it could save lives.

So this research is also an incredible economic engine, generating activity in every State in the country. NIH grants support high-quality research and high-quality jobs to help us grow our science and technology workforce, and it helps us not only in this country but throughout the world because other people will benefit from what we do. And, more importantly of all, this research generates hope. It generates hope. I hear nearly every day from constituents who come to my office. They share their stories. Sometimes they speak for themselves, and sometimes they speak for those who are no longer with us. The one thing that binds all of them together is our hope for tomorrow. I share their hope. I believe in the promise that biomedical research holds, but we are at a crossroads.

Congress must reject the devastating cuts to NIH proposed by President Trump. I have the honor of representing some of the most esteemed health centers in the country, if not in the world, the University of Maryland and Johns Hopkins. When I consider the magnitude of these proposed reductions, I think of all the potential that could be lost. I think of all the breakthroughs that could go unfunded and the researchers who could take their talents overseas. I also think of the families, like the Carrs, who have lost children to rare diseases; families like theirs have turned their pain into their passion to do their purpose, raising money and awareness in the hope of saving someone else the grief they experienced.

And so I pause to thank you for taking your pain and turning it into your passion to do your purpose.

But they cannot do it alone. Can't do it alone. They need a strong partner. Now is the time to recommit ourselves to leadership with investments that reflect our priorities of innovation and health promotion. Our budget cannot abandon those values. I look forward to hearing more about the innovative work of our panelists. And I call on all of my colleagues to continue supporting these and other programs with strong Federal investments, for this is our watch. What we do today will not only affect the people on Earth this moment, but will likely affect generations yet unborn.

With that, I yield back.

[Prepared statement of Mr. Cummings follows:]

Chairman CHAFFETZ. I thank the gentleman.



The chair notes the presence of our colleague, Representative Debbie Dingell, from Michigan's 12th District, whose constituent, Mrs. Tammi Carr, is testifying before the committee today. We appreciate her joining us today. We ask unanimous consent that Representative Dingell be allowed to fully participate in today's hearing.

Without objection, so ordered.

I will hold the record open for 5 legislative days for any members who would like to submit any written statements, but now it's time to introduce our panel of witnesses.

We're very pleased to welcome Mrs. Tammi Carr. She's the mother of Chad, who battled a rare pediatric brain cancer, and we're thrilled that she's here and that her family is here.

But I'd actually like to yield Ms. Dingell, Congresswoman Dingell, to help introduce you, Mrs. Carr.

Mrs. DINGELL. Thank you, Mr. Chairman, and thank you for your courtesy in allowing me to be here today. The Carr family has been friends of the Dingell family for a long time. And thank you for allowing Tammi—and not just Tammi, but she is accompanied by Jason and CJ and Tommy, and it's the strength and courage of all of them that has inspired us in our community.

On September 23, 2014, they got a diagnosis that none of us wants to hear, that their son had cancer. She'll tell you that detailed story more. After his diagnosis, our entire community, not just only in Ann Arbor, but in Michigan and the entire country, rallied around Chad and the entire family. We were all inspired by Chad's determination and his toughness during his battle, and that's how the phrase got coined, ChadTough.

On November 23, 2015—and I don't forget it because it was my birthday—Chad lost his battle, but heaven gained an angel. And what I hope that all of us see and hear in following Tammi and Jason's example is that they're trying to find a bright light on a cloudy day, and I know Chad is watching from Heaven as she tells her story today. So thank you for allowing her to be here.

Chairman CHAFFETZ. Thank you.

She is helping to also represent the ChadTough Foundation and, again, proactively. We can't thank you enough for being here, sharing your story, but also talking about the Foundation and what you'd like to see done, so I appreciate you being here.

We're also thrilled to have Dr. Mary Beckerle, who is the chief executive officer and director of the Huntsman Cancer Institute at the University of Utah Medical School. This is, being from Utah—and full disclosure, having worked for John Huntsman, Jr., as a campaign manager and chief of staff and his family, it's actually kind of how I came together with the Huntsman family was the fact that they had poured literally hundreds of millions of dollars in to fight cancer. And as somebody whose family members have passed away from cancer, to have the Huntsman Cancer Institute in our own backyard there in the Innermountain West, we're very, very grateful and thankful that Dr. Beckerle is dedicating her life and her talents to this very worthy cause. And we're glad to have you share more about what the Huntsman Cancer Institute is doing. It is a remarkable institution, and we're thrilled that you're here as well.

We also have Dr. Elizabeth Jaffee, who is deputy director of the Sidney Kimmel Comprehensive Cancer Center at Johns Hopkins University. I would appreciate it if we would have Mr. Cummings help introduce her.

Mr. CUMMINGS. Thank you, Mr. Chairman.

I'm truly honored to have Dr. Jaffee here today. She is at Johns Hopkins, and Johns Hopkins as you well know, is probably one of the greatest hospitals in the world. And it so happens to be smack dab in the middle of my district. They have done phenomenal work, and it is an honor to have her co-chairing the Blue Ribbon Panel and serving the people in Baltimore, and not only Baltimore, but the world.

And so I'm very pleased to have you, and thank you for being with us.

Chairman CHAFFETZ. Thank you.

And we also have Dr. Tyler Jacks, who is the director of the Koch Institute for Integrative Cancer Research at the Massachusetts Institute of Technology, certainly one of the most premiere and prestigious universities we have in this country, and they have done immeasurable work. And we're thrilled, Dr. Jacks, that you're here and joining us as well.

Pursuant to committee rules, witnesses are to be sworn before they testify. So if you will all please all rise and raise your right hands.

Do you solemnly swear or affirm that you will tell the truth, the whole truth, and nothing but the truth, so help you God?

Thank you. Let the record reflect that all witnesses answered in the affirmative. We normally ask that you keep your verbal comments to 5 minutes, but we'll give you great latitude. If you're on a roll, keep going. But your entire written statement will be made part of the record, and if there's any attachments or something else you want to share afterwards, that too will be made part of the record.

But, Mrs. Carr, we will start with you. You are now recognized. And by the way, you have to kind of straighten that microphone, pull it up close and personal, and make sure that the talk button is on. Mrs. Carr, you are recognized.

## WITNESS STATEMENTS

### STATEMENT OF TAMMI CARR

Mrs. CARR. Thank you, Chairman Chaffetz and Ranking Member Cummings and members of the committee. My name is Tammi Carr, and I'm here today to share about my son Chad Carr and his battle with a rare form of pediatric cancer.

September 23, 2014, as Representative Dingell mentioned, is a day that forever changed my perspective on life and on what is truly important. That day we took our 3-year-old son Chad for an MRI after a fall, an MRI that we had to fight for and an MRI that we were told was simply to confirm a possible concussion. They told my husband, Jason, and me that the MRI would take a couple of hours and not to be worried. Well, about 3-1/2 hours later, we were a little worried. And when we saw the look in the anesthesiologist's

eyes when she came to get us after the MRI, we knew we were in trouble.

She said they had found something, and that something was cancer. So what, as a parent, is your first reaction when you hear that your child has cancer? I can tell you at least ours: It was not to panic; it was to fight. Our questions were: How do we fix this? What's the first step? How do we get that tumor out? And what is the treatment plan?

To this day, the answer that we received completely blows my mind. As our adrenalin was pumping and we were ready for battle, we were told: "I'm sorry. Your son has diffuse intrinsic pontine glioma, or DIPG. It's a tumor in the brain stem. It cannot be removed. There's really no treatment plan. There's a zero-percent survival rate, and he has about 9 months to live."

So I'm sure mine is not the first story that you've heard about a child being diagnosed with cancer. It's sad. It pulls at your heart strings, right? But, please, think about the reality that we were given. You talk about hope. We were given no hope, zero. We weren't given a fighting chance. Our beautiful, spunky 3-year-old who had been running around the house 2 days before was now given a death sentence. How is that possible? How is it possible that Neil Armstrong's daughter was diagnosed with the same disease over 50 years ago, and the prognosis for our son and the treatment protocol were virtually the same today? How is that possible when we live in the most technologically advanced country in the world? How is it possible that our son was going to die, and there was absolutely nothing that we could do about it?

Well, after pulling myself off the floor of the ICU where I seem to have laid for hours, I decided we were not going to take that for an answer. That was not going to be Chad's story. There had to be a first child to survive, and that child was going to be ours. So we did all the research we could into clinical trials since there are actually a few dedicated researchers that are studying this disease. What we found is that they are mostly almost entirely funded by families like ours. They've committed their life's work to a disease that is unfunded, and they continue to watch children die year after year. How can this be okay?

These scientists do not receive any meaningful Federal research dollars because, as we have learned, pediatric cancer overall receives only 4 percent of all Federal research dollars, and this so-called rare disease, DIPG, doesn't make the cut for significant funding. Cancer kills about 2,000 children every year, and 300 of those deaths are from DIPG. Now, that may not seem like a lot of people in the grand scheme of things, but when you think of that many children dying year after year over so many years, you start to understand the thousands and thousands of years of life that these children never see. How many families need to be impacted before we can see some change?

We also learned that, second only to accidents, cancer is killing more children than anything else. What kind of cancer? Brain cancer. I literally believe it's becoming an epidemic. So why not focus on the hardest brain tumor to treat, the DIPG tumor that slowly took Chad's ability to walk, talk, swallow, and ultimately live? Surely if you make inroads with that most difficult type of cancer,

wouldn't that open the floodgates up to treat the more treatable tumors? That made sense to us.

So, while we were fighting for our child's life, we started the ChadTough Foundation to honor the toughest kid we knew and to become part of that change. We are proud to work alongside of other foundations and families who are similarly driven to make a difference with children who are suffering from DIPG. We created many memories as a family during Chad's battle. Chad spent every possible moment with his brothers, CJ and Tommy, who are here today and who he loved with every ounce of his being.

We shared our story with anyone who would listen, and we will continue to do that. We pushed Chad's physicians to think outside of the box, and we fought as hard as we could. We refused to give up. Unfortunately, after fighting for 14 months, our son Chad took his final breath on September 23, 2015. That is a moment I relive over and over in my head and something I think about every day and I will probably think about for the rest of my life. It's a moment that no parent should ever have to go through. It's a moment that I would not wish on my worst enemy, but we are doing our best to survive, and we live each day trying to honor Chad and all of the other DIPG angels.

The ChadTough Foundation raised \$1.5 million in 2016 for DIPG research in honor of our son. Today, our family is more focused than ever on being part of the progress for this disease, but it is just a drop in the bucket of what is really needed. Families who have lived a reality that no parent, grandparent, or sibling would ever want to know should not be alone in this fight. And believe me: this can become a reality for anyone. We never thought this would happen to us, and no one knows who it will be today, and no one knows who it will be tomorrow.

When I hear about those potential cuts to the NIH, as you said, it does, it just hits me right in the gut. There have been such great strides made around pediatric cancer, such as leukemia, because bright minds were asked to focus on treatments, and they were given the resources necessary to do so.

Pediatric leukemia, which was once considered a rare disease and 40 years ago had a 10-percent survival rate, now has a survival rate of nearly 90 percent. Chemotherapy was developed as a result of pediatric leukemia research. To think that the relatively small 4 percent research bucket for pediatric cancer research might be getting even smaller? The proposed 18 percent cut to the NIH budget would be devastating to all pediatric diseases, but especially so to rare diseases, such as DIPG, and at a time when there has finally been some momentum and discoveries made about the genetic makeup of these DIPG tumors.

In the last 5 years, we have seen explosive advancements in genomic data and other tools for cancer researchers to open up the battle against the most challenging and deadly pediatric cancers. Without Federal funding, though, we are very quickly going to lose ground in that battle. Federal funding is critical to recruiting the best and brightest scientists into pediatric cancer research, and no amount of family fundraising like ours is going to replace that. These scientists are already choosing to take pay cuts to do re-

search instead of seeking more lucrative private practice or industry jobs.

Foundation fundraising may help to increase the pace of that research, but NIH funding establishes the baseline to ensure that the research is pursued in the first place. If NIH funding is reduced, it will stifle progress for some of the most vulnerable people in our country who face devastating diseases like DIPG.

I ask that, when you consider the proposed cuts to the NIH budget, you think about my son Chad and all of the other children who were not given a fighting chance and who were not even given hope. You picture his face and you think about what might have been. Our family and others like ours will continue to work tirelessly in this fight, but we cannot do it alone, and we shouldn't have to. Without additional funding for research, children facing diseases such as DIPG will continue to have no hope for long-term survival. That is not a future that we can accept for these children because it is no future at all. Our children deserve more, and we must do better.

Thank you again for the opportunity to speak today, and I would be happy to answer any of the committee's questions.

[Prepared statement of Mrs. Carr follows:]

Thank you, Chairman Chaffetz, Ranking Member Cummings, and Members of the Committee. My name is Tammi Carr and I am here today to share about my son, Chad Carr, and his battle with a form of pediatric cancer. September 23, 2014 is the day that forever changed my perspective on life, and on what is truly important. That day we took our three-year-old son Chad for an MRI after a fall: An MRI that we had to fight for; an MRI that we thought was simply to confirm a possible concussion. They told my husband Jason and me that the MRI would take a couple of hours, and not to be worried. Well after three and a half hours, we were worried. And when we saw the look in the anesthesiologist's eyes after the MRI was complete, we knew we were in trouble. She said they had found something -- and that something turned out to be a brain tumor.

So as a parent, what is your first reaction when you're told that your child has cancer? I can tell you that it is not to panic, it is to fight. You ask: How do we fix this, what is the treatment plan, when do we start, how do we get that tumor out? Your adrenaline starts pumping and you are ready for the battle ahead. So we asked those questions and we got answers that to this day I honestly can't wrap my head around: "I'm sorry, your son Chad has Diffuse Intrinsic Pontine Glioma (or DIPG). It is a tumor in the brain stem. We cannot take it out. There is really no treatment plan. There is a zero-percent survival rate and he has about nine months to live." I am sure mine is not the first story you have heard about a child being diagnosed with a deadly cancer. It pulls at your heart strings and it's sad. But stop, and really think about what I have told you. Think about the reality that we were given. We weren't given any hope; we weren't given a fighting chance. Our beautiful, spunky, healthy three-year-old was just given a death sentence. How is that possible? How could it be possible that Neil Armstrong's daughter was diagnosed with this same disease over 50 years ago, and the prognosis for our son was virtually the same as it was for her? How is it possible that we live in the most technologically advanced country in the world and nothing had been done to make progress? How is it possible that our son was going to die and there was absolutely nothing that we could do about it?

Well after pulling myself up off of the floor of the ICU where I lay flat on my face for what seemed like hours, I decided we were not going to take that for an answer. That was NOT going to be Chad's story. There had to be a first child to survive and it was going to be my son. So we did all of the research we could into clinical trials, since there actually are a few dedicated researchers working on this disease. What we found is that they are almost entirely funded by families like ours. They have committed their life's work to a disease that is basically unfunded, and they have to watch children die year after year. How can this be okay? These scientists do not receive any meaningful federal research dollars because, as we have learned, pediatric cancer overall receives only four percent of all federal research dollars, and this so-called "rare" disease DIPG doesn't make the cut for significant funding. Cancer kills about 2,000 children in this country every year, and about 300 of those deaths are from DIPG. That may not seem like a lot of people in the grand scheme of things, but when you think about that many children dying every year, over so many years, you start to understand the thousands and thousands of years of life that these children never see. How many more families need to be impacted, and how many more lifetimes lost, before something changes? We also learned that second only to accidents, cancer is killing more children than anything else. And what kind of cancer? Brain cancer. So

why not focus on the hardest brain cancer to treat, the DIPG tumor that was slowly taking away Chad's ability to walk, talk, swallow, and ultimately to live? Surely if you make inroads with that most difficult type of tumor, wouldn't that open up the flood gates for the more treatable tumors? That made sense to us. So while we were in the midst of the fight for our child's life, we started the ChadTough Foundation to honor the toughest kid we knew, and to become part of that change. We are proud to work alongside of other foundations and families who are similarly driven to make a difference to children who are facing DIPG.

We created many memories as a family during Chad's battle. Chad spent every possible moment with his brothers CJ and Tommy, who are here today and who he loved with every ounce of his being. And we shared our story with anyone who would listen. We pushed Chad's physicians to think outside of the box, and fought as hard as we could. We refused to give up. Unfortunately, after fighting for 14 months, our son Chad took his final breath on November 23, 2015. That is a moment I relive over and over in my head. It is something I think about every day, and likely will for the rest of my life. It is a moment that no parent should ever have to go through. It is a moment that I would not wish on my worst enemy. But we are doing our best to survive. And we live each day trying to honor Chad and all of the other DIPG Angels.

The ChadTough Foundation raised over 1.5 million dollars in 2016 for DIPG research in honor of our son. Today our family is more focused than ever on being part of making progress against this disease, but it is just a drop in the bucket of what is really needed. Families who have lived a reality that no parent or grandparent or sibling would ever want to know should not be alone in this fight. And believe me, this can become reality for anyone. We sure never thought it would happen to us. No one knows who it will be today or tomorrow.

When I hear about potential cuts to the National Institutes of Health (NIH), it honestly hits me right in the gut. There have been such great strides made around pediatric cancers such as leukemia because bright minds were asked to focus on treatments and they were given the resources necessary to do so. Pediatric leukemia — which was once considered a rare disease and, 40 years ago, had a ten percent survival rate — now has a survival rate of nearly 90 percent. Chemotherapy was developed as a result of pediatric leukemia research. To think that the relatively small, four-percent research bucket for pediatric cancer research might be getting even smaller? The proposed eighteen-percent cut to the NIH budget would be devastating to all pediatric diseases, but especially so to rare diseases such as DIPG, and at a time when there has finally been some momentum and discoveries made about the genetic makeup of DIPG tumors. In the last five years, we have seen explosive advancements in genomic data and other tools for cancer researchers to open up the battle against the most challenging and deadly pediatric cancers. Without federal funding, we very quickly lose ground in the battle.

Federal funding is critical to recruiting the best and brightest scientists into pediatric cancer research, and no amount of fundraising by family foundations can replace that. These scientists are already choosing to take pay cuts to do research instead of seeking more lucrative private practice or industry jobs. Foundation fundraising may help to increase the pace of research, but NIH funding establishes the baseline to ensure that the research is pursued in the

first place. If NIH funding is reduced, it will stifle progress for some of the most vulnerable people in our country who face devastating diseases like DIPG.

I ask that when you consider the proposed cuts to the NIH budget you think about my son Chad and all of the other children who were not given a fighting chance. You picture his face and you think about what might have been. Our family and others like ours will continue to work tirelessly in this fight, but we cannot do it alone. Without additional funding for research, children facing diseases such as DIPG will continue to have no hope for long term survival. That is not a future we can accept; for these children, it is no future at all. Our children deserve more. We must do better.

Thank you, again, for the opportunity to speak to you today. I would be happy to answer any of the Committee's questions.



Chairman CHAFFETZ. Thank you. I really do appreciate it.  
Dr. Beckerle, you are now recognized for 5 minutes.

**STATEMENT OF MARY BECKERLE, PH.D.**

Ms. BECKERLE. Good morning. Thank you very much, and thank you for that incredibly inspiring story and your tremendous commitment to cancer research. We're all with you, 100 percent.

Thank you, Chairman Chaffetz, Ranking Member Cummings, and committee members, for your sustained interest in federally funded cancer research and your tremendous support for our sacred mission to really defeat cancer for all of humanity.

My name is Mary Beckerle, and I serve as CEO and director of Huntsman Cancer Institute at the University of Utah. Huntsman Cancer Institute is one of 69 National Cancer Institute-designated cancer centers. Our national network of cancer centers is focused on advancing scientific discovery and collaboration to improve cancer prevention and treatment for people around the United States and around the globe and for children like Chad.

Research is our best defense against cancer. Everything we know about cancer prevention and treatment today is based on research, including basic discovery science, which provides the new knowledge on which the health of our Nation depends.

It is an incredibly exciting time in cancer research, and I'm here to tell you that our national investment over the last several decades is making an impact. The cancer death rate has declined by more than 23 percent since 1991. In 1971, 1 in 69 people in the United States was a cancer survivor. Today 1 in 21 people is a cancer survivor, over 15 million of us in the United States today. In just the last 18 months, the FDA has approved 17 new cancer treatments, and many, many more are in the pipeline, thanks to our national investment in cancer research.

Despite this great progress, as we have just heard, we have so much more to do. Cancer is complex. We now know that cancer is not a single disease. Rather it is a collection of more than 200 different diseases. One in two men, one in three women will receive a cancer diagnosis in their lifetimes. In the USA alone, one person dies from cancer every minute of every day—every minute of every day.

Today, I want to share some examples of how one federally funded cancer center, Huntsman Cancer Institute, is making a difference for cancer patients and their families. At Huntsman Cancer Institute, a major focus is on cancer genetics. Huntsman Cancer Institute is a steward of the largest genetic database of its kind in the world with over 25 million records. This population database links family trees with clinical records. So we can detect cancer that runs in families. Our HCI scientists have worked with patients and their families to discover the genes responsible for many types of inherited cancer, including colon cancer, breast cancer, ovarian cancer, melanoma, and others.

So what does this mean for cancer patients today? Let me share a story about Gregg Johnson from Utah, an artist, husband, father of two. Members of Gregg's family have a disease that we call FAP. Certain family members have inherited a gene mutation that causes colon cancer at a very young age. Essentially, if you have

this mutation, you have 100 percent risk of developing colon cancer in your lifetime. Sophisticated genetic testing now enables us to identify which individuals in Gregg's family are at high risk for colon cancer so they can get proper screening and care.

Back in Utah today, thanks to cancer research, Gregg is outliving his family history. Gregg's mother and grandmother both died of colon cancer when they were in their 40s, way too young. Gregg is now approaching 60 years of age, thanks to federally funded research and what we call precision prevention, the use of knowledge about cancer genetics to prevent cancer.

Cancer genetics is also very important for children, and we are working on this actively at Huntsman Cancer Institute. Federal funding for childhood cancer has led to dramatic improvements in pediatric cancer survival, a 43-percent increase over the last several decades, as we heard from Mrs. Carr.

Just recently, an inherited form of childhood brain cancer was recognized, and we have been able to repurpose a drug that was developed for lung cancer to cure this disease in childhood cancer. But as highlighted by the Cancer Moonshot Blue Ribbon Panel, cancer still remains the leading cause of disease-related death in children. So we have so much more to do.

Finally, even in our great Nation, not everyone has equivalent access to the remarkable recent advances in cancer prevention and care. One underserved group is our rural and frontier residents. In the State of Utah, 96 percent of our landmass is rural and 70 percent frontier, with less than 100 or 7 persons per square mile, so very sparsely populated. Many of your States also have rural and frontier residents who live far from healthcare centers and have relatively poor cancer outcomes.

Federally funded researchers at Huntsman Cancer Institute have developed a new approach to deliver genetic counseling by telephone to reach people who are living in rural and frontier areas. We also developed a new tool for remote symptom management to support cancer patients and their families who live far away from medical centers while they're undergoing active treatment. Great progress in cancer prevention and treatment is happening at National Cancer Institute-designated cancer centers across our Nation, literally from sea to shining sea. Our Federal Government has an unmatched and irreplaceable role in supporting robust, consistent, and sustained investment in cancer research.

I, like Mrs. Carr and others, am deeply concerned that the proposal to cut NIH funding by 18 percent in fiscal year 2018 will have a devastating impact on our progress toward defeating cancer.

The need for investment in cancer research is great. The time is right. Research is the hope for the future. Research clearly saves lives, and we need to have a sustained investment in this lifesaving work. Thank you very much.

[Prepared statement of Ms. Beckerle follows:]

**Committee on Oversight and Government Reform  
United States House of Representatives**

**March 29, 2017**

**Federally Funded Cancer Research: Coordination and Innovation**

**Testimony by Mary C. Beckerle, PhD**  
Chief Executive Officer and Director  
Huntsman Cancer Institute at the University of Utah  
Distinguished Professor, Biology and Oncological Sciences  
Salt Lake City, UT

Thank you Chairman Chaffetz, Ranking Member Cummings, and Committee members for the invitation to join you to discuss innovation and coordination in federally-funded cancer research.

My name is Mary Beckerle and I serve as CEO and Director of Huntsman Cancer Institute at the University of Utah. I also oversee a research laboratory at HCI that has been funded by the National Institutes of Health (NIH) for over 25 years. My work is focused on fundamental aspects of cell biology and the application of this knowledge to a bone cancer called Ewing sarcoma. I also served last year on the NCI's Cancer Moonshot Blue Ribbon Panel.

Huntsman Cancer Institute (HCI) is one of 69 National Cancer Institute (NCI)-designated cancer centers, the highest designation possible for a cancer research institution. NCI-designated cancer centers undergo rigorous peer review by national cancer experts and thought leaders and must demonstrate depth and breadth of cancer research that spans from bench to bedside. Simply put, the goal of the Cancer Centers Program is to accelerate scientific discovery to improve cancer prevention and treatment. The Cancer Centers Program provides a national network for innovation and coordination that promotes collaboration and synergy to make the whole greater than the sum of the parts.

HCI is the only NCI-designated Cancer Center in the five-state Mountain West, which represents 17% of the continental landmass of the United States. The area we serve includes Utah, Nevada, Montana, Wyoming, and Idaho. Cancer patients and their families come to HCI from this entire region and beyond to access advanced cancer knowledge and care, including clinical trials that explore the most promising new cancer treatments. HCI is a hub for innovative cancer research with over 475 active research projects, which collectively were supported with \$62.9 million in research grant and contract funding in 2016.

Research is our best defense against cancer. Everything we know today about caring for people with cancer is built on decades of research, including basic discovery science, which provides the foundation on which the cancer prevention and treatment strategies of today – and tomorrow – depend.

We are in an incredibly exciting and promising time in cancer research, and our national investment is having an impact. Consider the following:

- The cancer death rate has declined by 1 percent each year for more than two decades, resulting in more than 1 million lives saved.
- The number of cancer survivors in the USA has quadrupled since the 1970s, reaching 15.5 million this year.
- According to the most recent AACR *Cancer Progress Report*, in just the last 18 months, the FDA has approved 17 new drugs to treat a variety of cancers. These treatments are saving and improving lives, and they only exist because of research.

In addition to the tremendous health benefits of the federal investment in cancer research for the health of our citizens, this investment also contributes to our economy and helps to retain our nation's prized status as the world leader in science and innovation.

Despite our great progress, we have **much more to do**. Cancer is complex: cancer research has taught us that cancer is not a single disease as originally envisioned when the War on Cancer was initiated in 1971 during the Nixon administration, but rather is a collection of more than 200 different diseases.

Cancer remains the major medical challenge of our time: today, one of every four deaths in our country is caused by cancer; we lose one person every minute of every day to this disease. Cancer is the **number one** cause of disease-related death among children in the USA. This year, in the United States alone, nearly 1.7 million people will receive a cancer diagnosis.

**Today, I want to share some concrete examples about how one federally funded Cancer Center, Huntsman Cancer Institute, is making a difference for cancer patients and their families. I will describe how our goals are coordinated with national strategic cancer priorities, as well as aligned with the cancer burden in our State and region.**

***Cancer Genetics and Colon Cancer:***

At HCI, a major focus is cancer genetics. HCI is the steward of the Utah Population Database, the largest genetic database of its kind in the world, with over 25 million records. In a way that fully protects individual privacy, information in the database, including "family trees", can be linked to clinical records, so we can detect cancer that runs in families and study cancer in the population of an entire State. This has allowed Utah scientists to discover the genes responsible for many inherited cancers, including colon cancer, breast and ovarian cancer, and melanoma.

What does this mean for patients? Consider this story about a Utah man named Gregg Johnson and his family history of colon cancer.

Members of Gregg's family have a disease called "FAP". Certain family members have inherited a gene mutation that means they almost certainly will develop colon cancer in their lifetimes. Sophisticated genetic testing has enabled us to identify which individuals in Gregg's family are at high risk for colon cancer and ensure that they are advised about cancer screening options that can detect cancer early when it is treatable, or prevent the cancer from developing in the first place.

Back in Utah, Gregg Johnson is hoping to outlive his family history. He shared his story with Vice President Biden when the Vice President visited Huntsman Cancer Institute in 2016. Gregg stood before a diagram of his family tree and pointed to his grandmother and his mother, both of whom died of colon cancer when they were in their 40s. Gregg is now approaching 60 years of age, thanks to genetic knowledge and annual colonoscopies to find and remove pre-cancerous polyps. We call this general approach "precision prevention". This is a promising area that was highlighted as a strategic opportunity by the Cancer Moonshot Blue Ribbon Panel.

Meanwhile, federal funding has continued to advance science to help families like Gregg's by supporting the study of the FAP cancer pathway by many labs around the country. And, just last year, HCI scientists reported very promising results from a study of the first prevention treatment for these colon cancer families.

Thanks to collaboration and coordination, we are able to conduct cancer research across the entire State of Utah. Along with Intermountain Healthcare, HCI studied more than 2 million individuals in the Utah Population Database and determined how family history of colon cancer impacts individual risk. This research led to new guidelines for colon cancer screening based on family history of disease that have been disseminated worldwide. In another statewide study, we learned why some colon cancers are missed during regular colon cancer screening, a finding that has led to new colonoscopy guidelines.

***Pediatric cancers:***

In Utah, we have the youngest population in the country, thus we have a disproportionate burden of children's cancers. At HCI we are testing an innovative new treatment for Ewing sarcoma, the second most common bone cancer in children and young adults. We are also addressing the long-term effects of pediatric cancer treatments that can compromise the quality of life of our growing childhood cancer survivor population. Parents of children with cancer are understandably desperate to know about the risk to their other children. Scientists at HCI have used the Utah Population Database to show that when one child in a family has an early onset cancer diagnosis, other family members do have elevated risk of developing cancer. This has led to new guidance for pediatricians and pediatric oncologists.

Federal funding for childhood cancers has led to dramatic improvements in the pediatric cancer five-year survival rate which has gone from 50% to about 80% since 1975. But there are still some childhood cancers for which progress has remained elusive, and cancer remains the leading cause of disease-related death in children. Here again, the Blue Ribbon Panel has put forward exciting proposals to accelerate progress in this

important area that will move be able to move forward if our national commitment for support of cancer research is sustained.

***Cancer in underserved populations:***

Finally, I will point out that even in this great nation, not everyone has equivalent access to the remarkable advances in cancer prevention and care. One underserved group that is not frequently highlighted is our rural and frontier residents. Ninety-six percent of the State of Utah is rural, with less than 100 persons per square mile, and 70% is frontier, with less than 7 persons per square mile. Recent research at HCI developed a new approach for remote symptom management to support cancer patients and their families that live far away from medical centers. This approach resulted in significant improvement in symptoms for patients in active treatment and also improved quality of life for the caregiver in the home. We have also tested a telephone-based method to deliver remote genetic counseling, effectively delivering information about inherited cancer risk outside of a major medical center.

Here I have described just a tiny amount of the important work going on at HCI as a result of federal funding for cancer research. This type of progress is replicated across our nation from sea to shining sea.

Our federal government has an unmatched and irreplaceable role in supporting cancer research. No other public, corporate, or charitable entity is able to provide the broad and sustained investment in research necessary to enable successes such as the ones I have noted today. Our continuing and future success requires an unwavering and bipartisan commitment from Congress and the Administration to continue to invest in life-saving biomedical research.

The need is great and the time is right. Research is the hope for the future.

I thank you for the opportunity to discuss this important national health issue and for your support of funding for the National Institutes of Health and the National Cancer Institute.

Chairman CHAFFETZ. Thank you.  
Dr. Jaffee, you're now recognized for 5 minutes.

**STATEMENT OF ELIZABETH JAFFEE, M.D.**

Dr. JAFFEE. Thank you. Chairman Chaffetz and Ranking Member Cummings, thank you for your leadership and dedication to this promising initiative and innovations that are turning previously deadly cancers into chronic diseases that allow patients to live long and productive lives.

Scientists in the United States lead the world in cancer research innovation and success, and continued investment will relieve cancer suffering for all Americans and hopefully prevent cancer development in our future generations.

I'm the deputy director of the Sidney Kimmel Cancer Center at Johns Hopkins, which is an NCI-designated cancer center. And today I would like to focus on four key areas that underscore the importance of supporting cancer research: the benefits of Federal funding; our current challenges; creating collaborations; and very importantly, training the next generation of scientists.

We are in the midst of a technological revolution, amassing huge amounts of information and using it to transform how we approach cancer treatment and prevention. To bolster this progress, the Beau Biden Cancer Cures Act with the 21st Century Cures Act is needed, in addition to the ongoing NIH and NCI budget allocations, to accelerate in 5 years what would take 10 years to move new discoveries into treatments for patients with cancer. Any cuts would slow future discoveries and innovation.

In just the last 6 years, 20 drugs that use the body's own immune system to kill cancer have been approved by the FDA for a variety of different cancers. Without the decades of investment in funding on the immune system, patients with these cancers would have died of their disease in less than a year. Instead, they are living years with good quality of life.

The rapid pace of scientific discovery and how the immune system sees cancer has opened the door to new areas of research that would not have been possible even 5 years ago. As one example, the NCI is now investing in laboratory research and cancer-screening studies to develop vaccines that can recognize the earliest changes in the normal cell and eradicate these normal cells that have small changes before they cause cancer. This is what we call prevention. Such prevention vaccines already exist, but we have the potential to do much more.

There are still many challenges to overcome. Treatments for rare cancers, including pediatric cancers, which we just heard about, are often neglected by the pharmaceutical industry. The NCI has supported networks of cancer centers that work together to conduct research and clinical trials focused on these rare diseases. One of them, the Cancer Immunology Trials Network, helped to lead the approval of a new immunotherapy drug for a rare form of skin cancer called Merkel cell carcinoma.

Another challenge is the need to identify barriers and provide solutions to people who typically lack access to the best cancer treatments. After studying this problem of clinical trials access among our own Baltimore populations of cancer patients, we narrowed the

gap between the minority and non-minorities who participate in clinical trials by 60 percent since 2001. Maryland was once the State with the second highest cancer death rate. Those deaths have plummeted in our State, and we are now the 31st. This significant reduction is due in large part to government-funded screening programs.

Collaborations between the NCI, the FDA, cancer foundations, advocacy groups, biotechnology and pharmaceutical companies, and patients, are critical to ensure progress in reducing cancer morbidity and mortality. Data from the collaborative effort of the Cancer Genome Atlas is used widely by researchers to generate genetic models of cancer development and drive the next questions in cancer biology and new drug development.

This investment has led to a new area of medicine, as you heard about, precision medicine, which utilizes the genetics of a patient's specific cancer to determine the best treatment. The NCI has since begun a national clinical trial called the MATCH trial which pairs patients with tailored options for clinical trials based on their tumor's genetics. This is the only trial of its kind in the Nation.

These examples highlight the incredible advances and innovations taking place in cancer research, but we can't end this progress with our current generation of scientists. Unfortunately, the perceived instability of government funding for research due to the threatened reduction in the NCI and NIH budget, without significant increases in the past decade, has created a crisis where young people are less inclined to pursue science as a career.

People's lives depend on this research. I brought with me today Stefanie Joho. She is a colon cancer patient. At 23, Stefanie's cancer had spread, and no treatment options were available to her. She found Johns Hopkins had a clinical trial using a new immunotherapy drug. The underlying scientific discoveries leading up to this trial were funded by the NCI. Within 3 months, Stefanie's tumor had shrunk 65 percent. More than a year later, Stefanie now remains healthy and is able to move on with her life.

The recent successes in science and medicine cannot continue without an increased government investment. Now is the time to recommit this investment in science and medicine and ensure the future health of our medical and technological industries, provide a sustainable career path for young scientists who will be the future innovators, and importantly, provide the opportunity to rapidly develop new cancer treatments and prevention strategies to once and for all eradicate cancer.

I would like to thank the entire committee for the opportunity to speak to you today, and I look forward to answering any questions you might have.

[Prepared statement of Dr. Jaffee follows:]



**Testimony for the Record  
Submitted to the  
United States House Oversight and Government Reform Committee  
For Hearing on  
Promising Initiatives and Innovations for Cancer Cures and Treatments**

**March 29, 2017**

**Elizabeth M. Jaffee, M.D.  
Deputy Director of the Sidney Kimmel Comprehensive Cancer Center at Johns Hopkins**

Chairman Chaffetz and Ranking Member Cummings, thank you for the opportunity to submit testimony on this timely and vitally important subject.

I commend you for your leadership and dedication to the promising initiatives and innovations that are already turning into durable treatments for patients with cancer. Decades of investment in cancer and biomedical research by our Government is paying off, and it's an exciting time. New treatments are being approved rapidly that are turning previously deadly cancers into chronic diseases that allow patients to live long and productive lives. Your efforts help research work for all Americans.

Scientists in the United States lead the world in cancer research innovation and success, and continued investment will relieve cancer suffering for all Americans and hopefully prevent cancer development in our future generations. I will focus on four key areas that underscore the importance of supporting cancer research: benefits of federal funding, our current challenges, creating collaborations and training the next generation of scientists.

I am the Deputy Director of the Sidney Kimmel Comprehensive Cancer Center at Johns Hopkins which is an NCI designated Cancer Center. Our mission is to reduce morbidity and mortality from cancer through research. Funding from the NCI gives Cancer Centers like ours the ability to support our scientists' research efforts, maintain and build core resources to develop new therapies, bring newly-developed therapies from the laboratory into clinical practice through clinical trials, and disseminate new scientific knowledge to the greater cancer community and the public. Many cancer centers like ours also work to reduce disparities in cancer care.

I am also the Dana and Albert "Cubby" Broccoli Professor of Oncology. I serve as Associate Director of the Bloomberg-Kimmel Institute for Cancer Immunotherapy at Johns Hopkins, and the Co-Director of the Skip Viragh Center for Pancreatic Cancer Clinical Research and Patient Care. In addition to these responsibilities, I am a member of 3 NIH funded graduate programs (Immunology, Cell and Molecular Medicine, and Pharmacology) and dedicate efforts to training the next generation of scientists. I am an internationally recognized expert in cancer immunology and translational research, with specific expertise in the early development of

immunotherapies for breast and pancreatic cancers. I have served on numerous academic advisory boards and currently serve as Chair of the National Cancer Advisory Board. I also served as a co-Chair of the NCI Blue Ribbon Panel for the national Cancer Moonshot Initiative. I am now the current President Elect of the American Association for Cancer Research. In summary, my 25-year career has been dedicated to finding cures for cancer and training young scientists.

#### **Benefits of federal investment in research**

We are in the midst of a technological revolution that is providing new insights into human biology and cancer. We are amassing huge amounts of information and using it to transform how we approach cancer treatment and prevention. To bolster this progress, the Beau Biden Cancer Cures Act within the 21<sup>st</sup> Century Cures Act was enacted. It comes at a fortuitous moment in this advancement of knowledge, providing a critical investment needed for new cancer research and precision medicine. This investment is needed in addition to the ongoing NIH and NCI budget allocations, to accelerate in 5 years what would take 10 years to move new discoveries into treatments for patients with cancer. It is important to stress that any cuts made to the NIH and NCI budget will slow future discoveries and innovation and will take away from the potential success of the 21<sup>st</sup> Century Cures Act that was intended to enhance the current and future NIH and NCI budgets.

I co-chaired the Blue Ribbon Panel, which engaged the entire cancer community to identify 10 priority areas ripe for the development of cancer treatments and prevention tools. These recommendations are a roadmap that leverages new advances already made in cancer diagnosis, prevention and treatment as a result of the long-term investment by our government in basic and translational research. There are many examples of recent successes that are already reducing suffering and improving the lives of patients with cancer.

One example of this is a cancer treatment that uses the body's own immune system to kill cancer. In just the last six years, a variety of "immunotherapy" drugs have been approved by the FDA for 20 different metastatic cancers that include malignant melanoma, renal cell carcinoma, non-small cell lung cancer, bladder cancer, head and neck cancer, and Merkel cell carcinoma. Patients with these cancers would have died of their disease in less than a year and now are living years with good quality of life.<sup>1-3</sup> This is the direct result of decades of investment in understanding how the immune system works and sees cancer. Our understanding the immune system has also led to the development of vaccines that can prevent cancers that are associated with two common viruses, human papilloma virus and hepatitis B virus. These advances are saving American lives and the lives of people worldwide.<sup>4,5</sup>

The rapid pace of scientific discovery in how the immune system sees cancer has opened the door to new areas of research that would not have been possible even 5 years ago. As one example, the NCI is now investing in laboratory research and cancer screening studies to develop ways to prevent the majority of cancers that are not due to viruses. Most cancers develop as a result of stepwise genetic changes that transform normal cells into premalignant cells and then into cancers. Scientists are now working on developing vaccines that can recognize the earliest changes in the normal cell and eradicate these changes before they cause malignancies. This progress is possible because of government funding in basic research on the immune system, genomic sequencing research through The Cancer Genome Atlas, and the development of genetically engineered mouse models that utilize the genome sequencing data to emulate how cancers develop in humans.

Early development of vaccines for cancer prevention is already paying off. Even for a deadly disease such as pancreatic cancer, we can now use vaccines in patients who undergo surgical removal of their cancer to prevent the cancer from coming back. Federal funding was used to develop one such vaccine approach at Johns Hopkins. We have treated 60 patients with this vaccine in the earliest type of clinical trial that aimed to determine if it can be effective. These patients were expected to have recurrence of their cancer within 1 year. Instead, some of these patients are celebrating their survival more than 10 years later. If it weren't for federal funding, this study could not have happened and these patients may not be alive today.

### **Current Challenges**

Although we are in a scientific revolution and making great progress, there are still many challenges to overcome. Several were identified by the Blue Ribbon Panel. One is the lack of progress that has been made for rare cancers. Among this category are pediatric cancers. Treatment for these cancers are not typically developed by the Pharmaceutical Industry due to their rarity. In contrast, the NCI has supported networks, including the Children's Oncology Group and Adult and Pediatric Brain Tumor Consortia, that provide the opportunity for multiple cancer centers to work together to conduct research and clinical trials focused on these rare diseases. These networks are critical for progress yet they are underfunded and fall short of the more common cancers when it comes to developing new clinical trials that have the potential to bring new treatments to patients. One such NCI-funded network -- The Cancer Immunology Trials Network -- led to the development of an immunotherapy drug for a rare form of skin cancer called Merkel Cell Carcinoma. The FDA approved this therapy within a few years of when the Network began its clinical trials. This is historic progress for people with this type of cancer and could not have happened without a government investment in clinical research. We need to do more of this and more quickly to bring these new agents to patients with different cancer types.

The NCI is the main source of funding for research on pediatric cancers. Pediatric brain tumors are among the most difficult cancers to treat, and a rare type called diffuse intrinsic pontine glioma or "DIPG" is even more challenging. DIPG affects the brain stem, with cancerous cells interspersed with healthy brain cells. Due to its structure and location, surgery is not possible and it is almost always fatal. Over the past 10 years, research has provided an improved understanding of this cancer including the identification of genetic mutations that are potential targets for new therapies.<sup>6</sup> These opportunities could only have occurred because of the Government's investment in this disease.

Another challenge is the need for enhanced population science research to identify barriers and provide solutions to people who typically lack access to the best cancer treatments. This research is needed for people in inner cities and rural areas, as well as for people of lower socioeconomic status, all of whom experience great disparities in cancer care. Government funded Cancer Centers provide the resources to conduct these population-based studies and offer solutions to overcome barriers to access. Johns Hopkins has made significant progress in the State of Maryland. Increasing minority access to care and recruitment into clinical trials has been a major priority for our Cancer Center. Maryland has more than twice the population of African-American citizens, compared with all 50 states. Cancer continues to affect minority populations disproportionately. Cancer death rates among black men are 27% higher than among white men, and 14% higher among black women when compared with white women.<sup>7</sup> We have done significant outreach in the community to advance our understanding of factors that influence disparities, determine biologic differences that may contribute, and provide better care, including ensuring all populations have equal access to clinical trials. After studying the problem of clinical trials access among our own populations of cancer patients, we narrowed the gap between minorities and non-minorities who participate in clinical trials by 60% since 2001.

Maryland was once the state with the second highest cancer death rate. Those deaths have plummeted in our state, and we are now the 31<sup>st</sup>. This significant reduction is due in large part to Government funded screening programs that have been implemented in low income areas and our inner cities. These screening programs have identified individuals with early colorectal, prostate, breast, and cervical cancers and have provided them with earlier access to the best treatment and clinical trials. The US Centers for Disease Control and Prevention reports that Maryland excels in cancer screening, and this is due entirely to federal funding.

As our population changes we continue to face new challenges. Obesity and diabetes are increasing among young Americans. There are a number of cancers that are starting to increase in incidence as a result, including, liver and intrahepatic bile duct cancers. Continued government resources are needed to understand the science that links these chronic conditions to cancer development so that new screening approaches and interventions can be developed to intercept an impending cancer epidemic.

### **Collaborations**

Collaborations between the NCI, the FDA, cancer foundations, advocacy groups, biotechnology and pharmaceutical companies, and patients is critical to ensure progress in reducing cancer morbidity and mortality. Government funding of early discoveries provides a foundation for new opportunities between academia, biotechnology companies, and pharma. These are important collaborations that could not occur without a federal investment in research because it is this investment that leads to the new innovations and early discoveries at the academic level that can then be further developed by biotech and pharma. We lead the world in technology development and research. We will only stay in the lead if we have increased government investment in the NCI and NIH.

The speed at which we are collecting data through cancer research makes collaborations and sharing of data critical. To make this data work well for us, we need to develop computational biology platforms for data processing and sharing. Our government stands poised to not only fund the generation of this data, but to also provide platforms for sharing it. The genomic sequencing

data generated by the federally-funded Cancer Genome Atlas is an excellent example. This data is used widely by researchers to generate genetic models of cancer development and drive the next questions in cancer biology and drug development. This investment has also led to a new area of medicine – precision medicine – which utilizes the genetics of a patient's specific cancer to determine the best treatment. The NCI has since begun a national clinical trial called the MATCH trial which pairs patients with tailored options for clinical trials based on their tumor's genetics.

The Blue Ribbon Panel identified data sharing as one of the top priorities. In addition to expanding the scientific data generated, the Panel recommended developing ways in which patients can access these data systems, input their own data for analysis by scientists, and also get “pre-registered” for clinical trials among all NCI-designated cancer centers. However, this recommendation can only be implemented with Government investment.

### **Next Generation of Scientists**

The state of science and medicine are at a Crossroads. On one hand, we are in the middle of a revolution that is turning decades of government investment into real treatments that are saving lives. On the other hand, the perceived instability of government funding for research due to the threatened reduction in the NCI and NIH budget without significant increases in the past decade has created a crisis where young people are less inclined to pursue this as a career.<sup>8</sup> The potential impact is grim – without the funding to launch a young scientist's research in the US, our young scientists are turning elsewhere. They are taking positions outside academia, leaving the US for countries that are using sustained funding to recruit our young scientists, or they are leaving science entirely. The lack of sustained investments in research and training is leading to a severe reduction in the scientific work force and recruitment of the best and the brightest to the field. We need to take a lesson from history. Before the World Wars, Germany dominated research and technology development. Americans pursuing a career in science had to learn the German language to read their original research. Since then, the US has dominated science, technology and medicine. This was due to the sustained government investment over the past 70 years. Such an investment had many important outcomes including the deciphering of the biology of many diseases that led to new therapies and the rise of the biotechnology and pharmaceutical industry that developed these new therapies, created many jobs, and made the US leaders worldwide. We need to grow biomedical research to show young scientists that these are long-term careers.

### **Summary**

Our worldwide dominance in cancer research has direct impact on people's lives. It is this research that has given colon cancer patient Stefanie Joho a new life. At 23, Stefanie's cancer had spread widely and she endured multiple regimens of chemotherapy. However, nothing worked. She was told she was inoperable and had no further options. She had debilitating pain and was down to less than 100 lbs. Stefanie's sister was determined to help and scoured the internet. She found a clinical trial using an immunotherapy drug for some forms of colorectal cancer at Johns Hopkins, and the underlying scientific discoveries spanning several decades leading up to this trial were funded by the NCI. Within three days of starting the immunotherapy drug, Stefanie's symptoms improved dramatically. Within 3 months, her tumor had shrunk 65%. More than a year later, she had a complete response. Stefanie remains healthy and is moving on with her life.

The recent successes in science and medicine cannot continue without an increased government investment. Now is the time to recommit this investment in science and medicine. A renewed and more robust investment will provide continued support for innovation, ensure the future health of our medical and technology industries, provide a sustainable career path for young scientists who will be the future innovators, and importantly, provide the opportunity to rapidly develop new cancer treatments and prevention strategies to once and for all eradicate cancer. Thank you again for the opportunity to speak to you today, and I look forward to answering any questions you might have.

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Chairman CHAFFETZ. Thank you.

And, Stefanie, thank you for being with us. God bless you. Glad you're here. Thank you.

Dr. Jacks, you're now recognized for 5 minutes.

**STATEMENT OF TYLER JACKS, PH.D.**

Mr. JACKS. Chairman Chaffetz, Ranking Member Cummings, and members of the committee, thank you for the opportunity to discuss the state of cancer research in our country and the transformation in cancer care that we are now witnessing. It's a privilege to be here today with Mrs. Carr and with my esteemed colleagues. My name is Tyler Jacks. I'm the David H. Koch Professor and the director of the Koch Institute for Integrative Cancer Research at the Massachusetts Institute of Technology. I was previously Chairman of the National Cancer Advisory Board, and I am a past president of the American Association for Cancer Research.

I've been actively participating in cancer research for the past 36 years, including overseeing a research laboratory at MIT currently focused on cancer genetics and immuno-oncology.

Along with Dr. Jaffee and Dr. Dinah Singer from the National Cancer Institute, I co-chaired the Cancer Moonshot Blue Ribbon Panel. Dr. Beckerle served on this panel as well. The panel's report described several exciting areas of opportunity in cancer research, treatment, and prevention, and we look forward to discussing this with you today.

Let me also express my appreciation to the Members of Congress for the passage of the 21st Century Cures Act, which was supported by overwhelming margins in both the House and the Senate and which includes funding for Moonshot programs for the next 7 years.

Cancer research discoveries made over the last few decades have led to powerful new classes of cancer medicines which are impacting the lives of thousands of cancer patients today. Other discoveries have led to new methods to detect the disease at earlier stages when conventional treatments are more effective. New insights into cancer etiology and risk factors are enabling new forms of cancer prevention and disease interception.

Still, despite this progress, based on current statistics, over the next 10 years, more than 15 million Americans will be diagnosed with cancer, including more than 150,000 children. This year, more than 600,000 Americans will die of cancer. Thus, although we have come a long way, our job is far from completed.

Today's hearing is particularly timely given the considerable uncertainty in the biomedical research community regarding President Trump's preliminary budget proposal for fiscal year 2018, which recommends a nearly 18-percent cut in the budget for the NIH. Such a budget decrease would have devastating effects on our Nation's efforts to make progress against cancer and other diseases and imperil the training of the next generation of biomedical researchers.

At the time of the passing of the National Cancer Act in 1971, the understanding of the basic processes that drive cancer was extremely limited. Since that time, Federal investment in fundamental cancer research has led to dramatic advances in the eluci-

dation of all aspects of the disease process. For example, in 1971, we did not know the identity of a single gene implicated in cancer development. Today, more than 500 cancer-associated genes have been found to be altered in human cancer. New anti-cancer therapies have been developed to counteract the effects of many of these changes, and there are many more to come.

While the development of these drugs requires significant R&D investment from private industry, as well as the involvement of clinical investigators, they are almost always rooted in basic science discoveries made in academic or government laboratories supported by the NIH and the NCI.

Federal support for biomedical research is essential for improving the health of our citizens. It is also critical to the economic welfare of the country. For example, it's estimated that, for every 1 percent reduction in cancer death rates, there's an approximately \$500 billion value to current and future generations of Americans. Advances in biomedical research also lead to massive investments from the private sector, including R&D spending in established companies as well as venture capital investment in the formation of new companies. In Massachusetts alone, there are more than 60,000 jobs in the biopharmaceutical industry.

The Federal investment in cancer research in the United States has paved the way for this progress. In the not-too-distant future, targeted therapies, immune-stimulating agents, nanotechnology-based drugs, including those developed based on progress at my Institution, at MIT, and more will be the mainstays of cancer treatment, leading to improved response rates, longer response times, and, increasingly, cures.

The United States has led the world in achieving this progress, and we should all feel a sense of pride for these accomplishments. Still, there is much more for us to do. Thank you again for the opportunity to appear before you today. I'm pleased to answer any questions that you might have.

[Prepared statement of Mr. Jacks follows:]



**Statement of Dr. Tyler Jacks, PhD  
Director, Koch Institute for Integrative Cancer Research at MIT  
Before  
The United States House of Representatives  
Committee on Oversight and Government Reform**

**For the Hearing entitled:  
Federally Funded Cancer Research: Coordination and Innovation  
March 29, 2017**

Chairman Chaffetz, Ranking Member Cummings and other members of the Committee, thank you for the opportunity to appear before you to discuss the state of cancer research in our country today and the transformation in cancer care that we are witnessing owing to the federal investment in our understanding and treatment of this disease over the past four decades.

My name is Tyler Jacks, and I am the Director of the Koch Institute for Integrative Cancer Research at the Massachusetts Institute of Technology (MIT), a National Cancer Institute (NCI)-designated Cancer Center. I was previously the Chairman of the National Cancer Advisory Board, and I have served as President of the American Association of Cancer Research (AACR). I am also a member of the Board of Directors of Amgen and Thermo Fisher Scientific. I have been actively participating in cancer research for the past 36 years, including overseeing a research laboratory at MIT currently focused on cancer genetics and immunoncology. I am not here as a representative of MIT nor as a representative of the NCI but as an experienced cancer researcher.

Along with my colleagues, Dr. Elizabeth Jaffee, who is also testifying today, and Dr. Dinah Singer, Acting Deputy Director of the NCI, I co-chaired the Cancer Moonshot Blue Ribbon Panel. This Panel was charged in the spring of 2016 by President Obama and Vice President Biden to establish the research agenda for the Cancer Moonshot. Dr. Mary Beckerle (also testifying today) was a member of the Panel as well. We are all pleased to talk about the recommendations laid out in the Panel's report (1), which describe several exciting areas of opportunity in cancer research, treatment and prevention.

This hearing is particularly timely given the considerable uncertainty in the biomedical research community regarding the recent release of President Trump's preliminary budget proposal for FY18, which recommends a nearly 18% cut in the budget for the NIH (2). Such a budget decrease would have devastating effects on our nation's efforts to make progress against cancer and

other diseases and imperil the training of the next generation of biomedical researchers.

President's Trump's budget follows recent bi-partisan support for the NIH and the NCI in Congress. This includes a significant budget increase for NIH in the FY16 appropriations after a 13-year period of decline as well as proposed further increases during in the FY17 budget negotiations. As this committee is well aware, the FY17 budget bill has not been passed, and the NIH is currently operating under a continuing resolution. Another indication of bi-partisan endorsement for the federal investment in biomedical research was the passage of 21<sup>st</sup> Century Cures Act, which was supported by margins of 392-26 in the House of Representatives and 94-5 in the Senate and signed into law by President Obama on December 13, 2016. A key part of this Act was the funding of the Beau Biden Cancer Moonshot, which provides dedicated support for the research priorities identified by the Blue Ribbon Panel. The Cancer Moonshot funding for FY2017 is \$300M. While highly valued, it is important to note that the Cancer Moonshot funds represent a fraction of the total budget of the NCI (\$5.21B in the FY2016 budget) (3). Sustained and robust support of the NIH and NCI budgets are required to fund the discovery research breakthroughs that enable projects such as the Cancer Moonshot as well as provide the resources necessary to train our Nation's cancer researchers of the future.

As outlined below, cancer research discoveries have led to powerful new classes of cancer medicines, which are impacting patient lives today. Other discoveries have led to new methods to detect the disease at earlier stages when conventional treatments are more effective. New insights into cancer etiology and risk factors are paving the way for new forms of cancer prevention and disease interception. Still, despite this progress, based on current statistics, over the next decade it is estimated that more than 15 million Americans will be diagnosed with cancer, including 150,000 children (1). In 2017 alone, more than 600,000 people will die from the disease in this country (4). Cancer is the second leading cause of death in the United States, following closely behind heart disease. Globally, cancer causes more deaths each year than HIV/AIDS, malaria, and tuberculosis combined (5). Thus, although we have come a long way in our detailed understanding of cancer and have begun to apply that knowledge in the form of better ways to treat and control the disease, there is much more to be done.

### **Cancer research is the foundation for clinical progress**

At the time of the passing of National Cancer Act of 1971, the understanding of how cancer cells arose in the human body, how they spread to distant sites in the process of metastasis, and how they responded to treatments was extremely limited. Since that time, the federal investment in fundamental cancer research,

which occurs largely through NIH/NCI grants to academic investigators as well as the support of government laboratories, has led to dramatic advances in our understanding of all of these processes. As an example, in 1971 we did not know the identity of a single gene implicated in cancer development. Today, more than 500 cancer-associated genes have been identified, in which alterations promote the initiation or progression of cancer. Federal investments such as the Human Genome Project provided a roadmap to find and explore the function of these genes. The NCI's Cancer Genome Atlas Project has supported the detailed analysis of thousands of cancer samples across multiple cancer types to provide an increasingly clear picture of the diversity of mutations and other alterations that underlie tumor development (6). The functional characterization of these genes and cellular processes is likewise primarily the product of discovery research programs funded by the federal government. These efforts have been greatly facilitated by the establishment of the NCI Cancer Centers Program, which is composed of 69 NCI-designated Cancer Centers located across the United States, which are engaged in both cancer research and cutting-edge cancer care. To facilitate the dissemination of the latest advances to patients outside of the reach of these Cancer Center and improve access of rural and underserved populations, the NCI has also established the Community Oncology Research Program (NCORP), which is a large network of cancer research and clinical centers.

Owing to these efforts, we are witnessing a revolution in the treatment of cancer. An increasing number of cancer patients are now being treated with forms of "precision medicine," drugs that act on specific molecular alterations in an individual's cancer cells. Because cancers differ from organ to organ and from patient to patient, a detailed understanding of the genetic and other changes present in a given patient's cancer allows for the use of the most appropriate therapy for them. Drugs such as Herceptin (Genentech/Roche), used in the treatment of a subset of women with breast cancer, and Gleevec (Novartis), used in the treatment of a form of leukemia, are two well-known examples of powerful precision cancer medicines. New treatments for lung cancer have also been developed that target the products of specific mutant genes. Several more of these precision cancer medicines have been approved by the Food and Drug Administration (FDA) and many more are in clinical testing. While the development of these drugs requires significant research and development investment from private industry as well as the involvement of clinical investigators, they are almost always rooted in basic science discoveries made in academic or government laboratories supported by the NIH and the NCI.

The characterization of genetic profile of an individual's cancer at the time of diagnosis is becoming a routine practice in major medical centers today. This genetic analysis complements more traditional methods in pathology, with the goal of tailoring the therapy to a well-defined subtype of a given cancer type. The

NCI has recently launched the Molecular Analysis for Therapy Choice (NCI-MATCH) trial to test the clinical benefit of assigning patients to specific drug regimens based on the genetic profile of their tumor (7). Multiple NCI-designated Cancer Centers and NCORP sites are participating in the NCI-MATCH trial. The results of this and similar clinical trials will inform clinical practice for all cancer patients in the future.

Basic research into the function of the immune system and its interaction with cancer has allowed for the development of a series of new medicines that stimulate immune responses against cancer cells. Several of these drugs have been approved by the FDA, and they are having remarkable effects for patients with multiple types of cancer. Hundreds of clinical trials are ongoing to test new immuno-oncology drugs and other forms of treatment, which are also showing great promise. The development of this new class of medicines, which are expected to be the backbone of cancer treatment of many forms of cancer in the future, can be traced back to research funded by the NIH and the NCI.

#### **Recommendations of the Cancer Moonshot Blue Ribbon Panel**

Over the first half of 2016, the Cancer Moonshot Blue Ribbon Panel engaged more than 150 scientists, clinicians, medical professionals, industry representatives and patient advocates to develop a set of recommendations that would form the basis of the Moonshot research effort, if funded. The Panel was tasked by Vice President Biden to define opportunities that would allow the field to achieve in five years that would have otherwise taken ten without this dedicated funding. Through various outreach efforts, the Panel also considered more than 1,600 suggestions submitted by the cancer research community. The product of this effort is the Blue Ribbon Panel Report, which lists ten major recommendations (1). Importantly, the Panel envisioned that the research efforts undertaken by the Moonshot to address these recommendations would involve the collaborative efforts of academic laboratories, government laboratories and administrators as well as industry. Moreover, these “mission-focused” efforts were expected to complement the ongoing discovery research programs funded through the NCI research portfolio from its annual appropriation.

Of these important recommendations, I will focus here on just one: the establishment of National Cancer Data Infrastructure for Sharing and Analysis. In an era of increasingly complex and high throughput data related to cancer, it is critical that this information be stored in a fashion where it can be readily accessed and analyzed by researchers, clinicians, and, where appropriate, patients. This recommendation anticipates the development of a series of interconnected and interoperable databases as well as analytical methods that would store cancer-related information and improve data access and analysis. Although efforts to achieve related goals are underway in many centers in the

country, as well as at the NCI, the Panel recommended that a national resource was necessary to ensure appropriate access to data and improve the interoperability of the stored data. The successful execution of this recommendation will require the cooperativity and collaboration of the public and private sectors, with the NCI playing a critical coordinating role.

Across all of the recommendations of the Blue Ribbon Panel, there is a strong emphasis on the importance of technology development in advancing progress against cancer. This is an area of particular interest to me, in part because the Koch Institute for Integrative Cancer Research was formed to bring together cancer scientists and cancer-oriented engineers at MIT. Thus, we have a strong emphasis on technology development as well. Of note, the formation of the Koch Institute was inspired by grants from the NCI that funded interdisciplinary teams of investigators in areas such as computational and mathematical modeling of complex processes in cancer and nanotechnology applications to cancer treatment and early detection. The continued funding of interdisciplinary, collaborative approaches to cancer is critical to achieving the goals of the Cancer Moonshot and for advancement of cancer research discoveries more generally.

The passage of the 21<sup>st</sup> Century Cures Act provides \$1.7 billion to support the Cancer Moonshot, with \$300 million allocated for FY2017. The NCI has formed a series of implementation teams to begin to plan for use of these funds in support of research to pursue the recommendations of the Blue Ribbon Panel. The funding structures, collaborative mechanisms, and review and oversight processes that are used to launch and monitor this effort will be key to its success. Because of the need for flexibility in funding through this program, Congress should consider granting Other Transaction Authority to the NCI in the use of these funds.

#### **The importance of investment in biomedical research on training and the economy**

Federal support for biomedical research is essential for improving the health of our citizens. It is also critical to economic welfare of the country. For example, it is estimated that for every 1% reduction on cancer death rates there is an approximately \$500 billion value to current and future generations of Americans; effectively curing or preventing cancer is estimated to be worth \$50 trillion to the US economy (8). Advances in biomedical research broadly and cancer research more specifically leads to massive investment from the private sector, including research and development investment in established companies and venture capital investment in the formation of new companies. In Massachusetts alone, there are more than 60,000 jobs in the biopharmaceutical industry.

The Koch Institute at MIT is located in Kendall Square in Cambridge. This area has undergone a remarkable economic revitalization over the past three decades and is now the leading center of biomedical research and development in the world. The numerous companies that have located their headquarters and research operations in the Kendall Square and Greater Boston area have chosen to do so because of the proximity of great research universities such as MIT and Harvard. These universities depend on the NIH to support their biomedical research enterprise. Biomedical research in academic laboratories is an engine in the innovation economy in the United States. The NIH budget is its major source of fuel.

Most biomedical researchers—whether they work in academic, government or industry laboratories—receive their training at research universities. Graduate students, post-doctoral fellows, MD/PhD students, and technical staff are trained through their involvement in research projects in academic laboratories. The bulk of the projects that they pursue are funded through NIH grants. Thus, the NIH is a critical component of readying the American workforce to participate in this sector of the innovation economy. Reductions in funding, like those proposed in President Trump's preliminary FY2018 budget document, would have a direct and devastating effect on the number of trainees that could be supported. Such cuts would lead to significantly fewer grants funded and the likely closure of many biomedical research laboratories around the country. This is especially striking since the support of science in other countries is increasing at this time. As one example, the 13<sup>th</sup> five-year plan recently announced by the Chinese government includes a proposed 9.1% increase in science funding (9). These developments threaten to undermine the dominant position that the biomedical research in the United States currently maintains.

The increase in funding for the NIH in the FY2016 budget was a welcome relief for our field after 13 years of stagnant budgets. This period saw the success rates of grant applications drop into the low double digits or, in some cases, single digits. Grant awards were cut and overall budgets were not sufficient to keep pace with inflation. Collectively, this trend in funding led many young people to question the wisdom of a career in academic biomedical research, thus threatening the pipeline of talent for years to come. The FY2016 increase for NIH and the positive negotiations for the FY2017 budget were widely seen as a bi-partisan reaffirmation of the importance of biomedical research for the health and economy of the United States. The passage of the 21<sup>st</sup> Century Cures Act was similarly positive. The President's preliminary FY2018 budget document has had a chilling effect on our colleagues and on our trainees. If it were to stand, the effects on the American biomedical research enterprise would be felt for years to come.

### Concluding remarks

The federal investment in cancer research in the United States that has occurred since the launching of Richard Nixon's War on Cancer has produced a deep understanding of a wide range of cellular and physiological processes that are dysregulated during cancer development. These insights have enabled the development of powerful classes of new anti-cancer agents that are benefitting thousands of cancer patients today. In the not-too-distant future, targeted therapies, immune-stimulating agents, nanotechnology-based drugs and more will be the mainstays of cancer treatment, leading to improved response rates, longer response times and, increasingly, cures. The United States has led the way in achieving this progress, and we are poised to do a great deal more.

I would suggest now is the time to redouble our efforts, not retreat.

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Chairman CHAFFETZ. Thank you. Thank you all. We appreciate that.

We're now going to recognize the gentleman from Florida, Mr. DeSantis, for 5 minutes.

Mr. DESANTIS. Thank you, Mr. Chairman. And thanks for holding the hearing. I think this has been a phenomenal panel.

I thank the witnesses. It's a very important issue.

Dr. Jacks, you mentioned the benefits; that you do the research, the breakthroughs that lead to a lot of value for society. I think you said 500 billion. It just seems to me that we did the 21st Century Cures Act, which I think was important. Obviously, we're going to have to fund that. But, as we get breakthroughs, even as a fiscal matter, it seems to me you're going to save billions and billions of dollars because most of our cancer patients are older. Most of them are on various government programs. So it's obviously great for saving lives, but even here in the Congress, as we're dedicating money to this, isn't it the case that we'll probably save money in the long term?

Mr. JACKS. I think there is no doubt about it. The economic benefits in the treatment of cancer and ultimately cures for cancer will play out in many ways, including reducing the costs of health care for those individuals and increasing productivity amongst our citizens. So, in both respects, the economic payoff of this relatively small investment is staggering.

Mr. DESANTIS. And so, with that in mind, what are the funding requirements under 21st Century Cures and NIH's work in cancer research? What do we have to be doing here in the Congress? And anyone that wants to chime in on that.

Mr. JACKS. Well, I'm happy to start. Funding the 21st Century Cures Act was a very important step. It provided dedicated funding to begin the initiatives that we outlined in the Cancer Moonshot and Blue Ribbon Panel. And so we're grateful for that, and that work is already beginning.

I think, frankly, the bigger issue is the NIH budget and the consequent effects on the NCI budget. We have seen increases. The Congress actually passed a \$2 billion increase for NIH in fiscal year 2016. That was a welcome relief after a long period of stagnant budgets and opened up the doors to new ideas and transformational new projects. The fiscal year 2017 likewise had an increase of \$2 billion from the Congress. I think advances or increases of that magnitude will be important for a sustained period of time to allow us to deliver on the promise of biomedical research.

Mr. DESANTIS. Now, we do a lot of oversight in this committee about how government spends money, and even the NIH, you do see studies where they spend millions of dollars on studying binge drinking in sororities or stuff the taxpayers look at, and I think that should be definitely viewed, and we can criticize that. But can you reduce funding for NIH to the extent that's being discussed without negatively affecting cancer research, Dr. Jacks?

Mr. JACKS. Absolutely not. If the budget proposal that was put forward by President Trump were to be enacted, estimates are that zero new grants would be funded next year by the NCI, zero new grants. So the simple answer to your question is no. We could not



pursue the exciting forms of cancer research that we're currently undertaking if that proposal were to be enacted.

Mr. DESANTIS. Go ahead.

Ms. BECKERLE. Perhaps I can comment as well. About 80 percent of the NIH budget actually is dispersed to the States to the cancer centers for research, for training, for centers. And as Dr. Jacks said, this proposed \$5.8 billion cut would be absolutely devastating. No new grants. It affects the economy of our States because every dollar of Federal funding turns into new jobs and economic growth within our States. And most importantly I think to highlight is the critical importance and the critical impact of this type of a cut on the pipeline of trainees that really is the future of cancer research and future of biomedical research in our country. These folks would not be able to be funded, and we would lose a whole generation.

Mr. DESANTIS. I know, because I know there is private money that's involved, but it just seems if there is that little government money available, then you can't even leverage the private as much as you would. Is that fair to say?

Dr. JAFFEE. That's very fair to say. We couldn't leverage the private money. But also I think the NIH money allows for innovation. Often the private money is geared towards specific interests of that private foundation. So we will lose innovation in this country if we decrease this budget.

Mr. DESANTIS. Great. Well, I appreciate the testimony. I think that this is very important.

And, Mrs. Carr, thank you. It was great testimony.

And I think most of the members on this committee believe that what you guys are doing is very, very important. And there's a lot of different things—we police waste on this committee. That's kind of our job, and there's a lot in the government that we can point fingers at, but I think this is one area where clearly the money that we are putting in has the potential to really do a huge amount of good for people's lives, and as we said at the beginning, for our Nation's fiscal solvency going forward. So I thank you guys.

And I yield back the balance of my time.

Chairman CHAFFETZ. The gentleman yields back.

We would like to ask unanimous consent to allow Mrs. Dingell to ask the next round of questions.

Without objection, so ordered.

Ms. Dingell, you are now recognized for 5 minutes.

Ms. DINGELL. I want to thank all of you. I'm just happy to be here to support my friend Tammi.

So thank all of you, all of the panel.

Let me just ask some questions of Tammi so we could talk about some of the issues and see the challenges.

The ChadTough Foundation raised over \$1.6 million last year for DIPG research. Can you talk about the type of research the foundation is supporting and your vision for the future?

Ms. CARR. Yes. Well, for us, in our infancy really, the first year of this foundation, that was a tremendous amount of money to raise. But think about that. You guys see dollars all the time. That's nothing. So, obviously, we are supporting efforts through what is called The DIPG Collaborative. We are a small group of family foundations. We are the only people that are funding this

disease. So we are trying to focus our efforts together and not reinvent the wheel. All of our family foundations come together in the DIPG Collaborative where we have a medical advisory board that looks through our proposals that come through, helps us to find the most efficient ways to get the biggest bang for our buck, because there is so little funding for this disease. So we're really efficient, which I figured this committee would appreciate, and we pool our resources together to make the biggest impact.

The ChadTough Foundation also individually is supporting significantly at the University of Michigan where we are working to create a pediatric brain tumor center that focuses strictly on pediatric brain tumors. We are funding a research professorship at the center through the ChadTough Foundation, and then I am also working with physicians there to raise separate dollars that go directly to the University of Michigan. We have raised 19 million out of 30 that's needed to get the center started. So those are just a couple of examples.

Ms. DINGELL. Thank you.

You've been a tremendous advocate for all children since this tragedy. Can you talk about your experience meeting other families across the country that have been impacted—not only by this disease, but I've met other families that have been hit by cancer—that you've met? Can you talk about that experience?

Ms. CARR. Sure. People say this is not a club that anyone wants to join. That's the first thing I'll tell you. These families are put through a lot while they're trying to get their child healthy, if that's possible, and they're—you know, there are strains on every aspect of their life. They quit their jobs. They change their life around. They are amazing people.

And I didn't step into this world willingly, but now I'm hopeful that I can be of help in any way possible. Not everyone who goes through this battle wants to do what we're doing, and I appreciate that. This is an individual journey, and people take the steps that they feel right. Some people don't want to have anything to do with it afterwards, but I guess there's a group of us that don't feel that way. And in all honesty, it helps me to get through the day to know that we're trying to create something good out of a horrible situation.

So you know, our hope, and several other families that we work with, is that we can be advocates for those who don't find this to be the way they want to follow their next steps, that this is—this isn't for everybody, and some people—I don't think anything wrong if they want to crawl in a hole because I get it. But for me personally, I need to see something good coming out of this, so anything I can do to help.

Ms. DINGELL. So I've got 1 minute left, so I'm going to ask you, what would you say to Congress today that you and families of children with pediatric cancers of any kind, what is it you hope for?

Ms. CARR. I hope that you fight as hard as you can against this proposed budget cut. This is just devastating, and you know, when I think about DIPG as an example, 2-and-a-half years ago, when Chad was diagnosed, they talk about the precision medicine. Biopsies for these DIPG tumors were not even commonplace. We were not encouraged to get a biopsy on our son's tumor because it's in

the brain stem and it's dangerous and things can go wrong. Now it's become more commonplace. They figured out how to do that.

In this 2-and-a-half years we've seen such progress, they've taken—we donated Chad's tumor postmortem, and Michigan did some sequencing. We didn't have the biopsy tumor, the diagnosis, biopsy tumor, but we had the postmortem, and they found a histomutation that they never knew existed in DIPG before. And when I heard that, you know, they said we know some—we have some medicines that we know can impact this, and I mean, I lost it. So are you telling me that if we had had this information 2-and-a-half years ago, could something have been done? And they said, we couldn't have even sequenced this tumor this way 2-and-a-half years ago.

So you think about that progress, and Chad was also, had the ability to participate in a trial at Sloan Kettering University in New York where it's a CED trial where they insert a catheter directly into the tumor because passing the blood brain barrier is a big issue for pediatric brain tumors. We felt obligated that we needed to do something. If it was not going to hurt him, and you know, again, maybe it would—maybe it would cure him. At the time, that's what we were thinking. That wasn't the case, but they've learned so much from that trial.

And there are so few clinical trials available as it is, and I look at this budget and I think about all this promise, even just around this one disease and the fact that zero new grants would come out, that leaves, just this one disease, that leaves it all in the hands of families like ours. Nothing is going to happen from that. I mean, we are doing our best. We are doing our best to raise something, but without the support of the NIH, all that progress is going to go downhill, and not having those new scientists, those new researchers, those bright minds say, "I want to commit myself to making a difference," if they have no funding, how can they do that?

It's just to me it's senseless, and when you think about 600,000 people lost a year, that is—there is nothing worse. How can we not be focussing on this? How can this not be the number one priority when we talk about budgets? And again, maybe you're right, maybe it takes someone going through this for them to really get it. I don't wish anyone to go through this to really get it. Listen to what we're saying. You don't want this to happen to anyone you know.

So my thought would be, anything that anyone can do to fight these budget cuts, there needs to be increases, not decreases.

Chairman CHAFFETZ. Well said. Thank you for sharing that. Thank you.

Ms. DINGELL. Thank you Mr. Chairman and ranking member for including me today.

Chairman CHAFFETZ. Thank you. We'll now recognize another gentleman from Michigan, Mr. Paul Mitchell is now recognized for 5 minutes.

Mr. MITCHELL. Thank you, Mr. Chairman.

Mrs. Carr, first, let me say I couldn't be more touched by your story. I have a 6-year-old at home. Please be assured, I have already signed onto a letter urging full funding of the NIH. There's

a lot of ways that we can save money in our bloated government. I've been here 90 days, and already we've seen a variety of ways we could save money besides not addressing the health challenges we have in this country.

Pediatric cancer is one of so many. Like many on this group, we've lost family members, I have, to cancer, never a child. I can't fathom that. I thank you for your bravery in taking this challenge on because you're right, crawling in a hole can't be the answer.

Let me ask you one question. Does anybody have any inkling to us to share with us why it is that NIH would only allocate 4 percent of their money, their grants to pediatric cancer versus all the other things? Is there any insight you could provide us on why that decision, because it seems to me to be a paltry amount, a paltry percentage. Is there any insight as to why?

Ms. CARR. I agree with you. Four percent is not enough. I think our kids deserve a whole heck of a lot more than 4 percent, and I have fought that from day one. I don't think people realize that either. I don't think that's something that people realize. You know, they think about cancer, and a lot of times you think about kids, right, you know, you see all these advertisements with these little bald children and you think, okay, that's where my dollar is, that's where they're going, and they're not, and I think that's a shame.

As to why, I think, unfortunately it's numbers and it's money, and you know, pharmaceutical companies don't want to invest in something when they're not going to, you know, sell thousands and thousands of drugs. I mean, that's the reality of it.

So that's one thing that's—that I could say for sure is part of the issue, and it's wrong.

Mr. MITCHELL. Anybody else on the panel can shed some light to that?

Ms. BECKERLE. Yeah, perhaps I could comment as well. I think that one of the things that we're appreciating right now is just the incredible opportunity in childhood cancer research, and that was one of the areas that was highlighted by the Cancer Moonshot effort.

In addition, I think that much of the research money that is provided by the NIH and the NCI goes to what we could call sort of fundamental cancer biology that is not targeted to a specific disease area but yet has relevance to many different disease areas. And so I want to reassure you that a lot of research at NCI and NIH is focused on areas quite relevant to pediatric cancers.

In fact, my own laboratory is funded by a basic science grant that we study how cells move, and that's relevant for metastasis, and the pathway that my lab discovered is misregulated in a rare childhood cancer called, "Ewing's Sarcoma," and we're actually working on Ewing's Sarcoma as part of that research program.

Mr. MITCHELL. Thank you.

My time is grossly expired. I apologize. Mr. Chair, I'd like to suggest maybe we could have a discussion about a hearing on oversight of how it is that NIH does make determinations of grants and what the percentages are to various areas because I think it's worth some discussion.

Thank you for your patience.

Chairman CHAFFETZ. Thank you.

I now recognize the ranking member, Mr. Cummings.

Mr. CUMMINGS. Mrs. Carr, I want to thank you very much for sharing your story with us. Can you tell us a little bit about your son? You probably knew him better than anybody else.

Ms. CARR. Yeah, he was a really special boy. He was beautiful and he was funny and he loved his family. He loved animals. He wanted to be an animal doctor when he grew up. That's what he would have told you. He carried two doggies around with him wherever he went named Barley and Frederick. Frederick is with him and Barley is with me.

He was an amazing boy with an eclectic taste in food. He liked miso soup and olive muffalata, and peppers, and he liked to have fun. He loved life.

Mr. CUMMINGS. And you said something that kind of struck me when you said—these weren't your exact words, but you said we mourn for what could have been.

Ms. CARR. Every milestone. You know, he would have gone to kindergarten last year, or this year. You know, you watch his friends and you see them reach a milestone. You see them learn to ride a bike, and he wanted to do that. You know, he'd say: When my leg starts working again, I want to ride a bike. So yeah, it's horrifying, and it isn't right.

Mr. CUMMINGS. We want you to—you know, one of the things that I talk about with my staff is that the limited amount of time that we have on this earth, we need, in whatever we do, to do everything in our power to be effective and efficient because we can spend a lot of time going in circles, and then you look back at your life and you're frustrated.

Dr. Jaffee, when you hear somebody like Mrs. Carr come in, if she were to ask you how do I make sure—and the others of you can chime in—that I use my energy and the resources and hand to be most effective and efficient, what would you tell her?

Dr. JAFFEE. I think that's a really important question, and I would tell her that we need her partnership. I think, in the past, we didn't appreciate as much what patients and family members can help with and guide us and tell us what are the important questions and reminding us that we're not concentrating on the cancers that we need to concentrate on. And so that's what I would tell her, please be our partner in this.

Mr. CUMMINGS. And Mrs. Carr, I would like to get your reaction to a short video clip of our White House spokesman, Sean Spicer, answering a question about the cut.

Ms. CARR. I know what clip it is.

Mr. CUMMINGS. Oh, you're familiar with it?

Ms. CARR. I've seen it.

Mr. CUMMINGS. Someone going to put it up?

In this clip, he tries to claim that the massive reduction in funding is not really a cut at all.

[video played.]

Mr. CUMMINGS. Mrs. Carr, do you agree that NIH is currently wasting about \$6 billion a year?

Ms. CARR. No, and I would ask, I wonder if he's ever had an experience like ours or known of anybody who has, or President

Trump, I would ask him the same question because when he says it's a waste, without more funding, they're—right now, DIPG research, if I specifically look at that, is getting zero dollars funded.

So is it a waste to focus on this disease? Because without additional funding, there is zero funding coming. There will be nothing. So I don't think focussing on one of the most difficult tumors and hopefully seeing some trickle down to some of the other more treatable tumors would be a waste.

Mr. CUMMINGS. So you would agree that both Democrats and Republicans need to work together—

Ms. CARR. I don't think this should be a partisan issue.

Mr. CUMMINGS. I agree.

Ms. CARR. I mean, why—think of how many people's lives are being lost in this country. More than—anything but axes, I just—that, to me, I don't understand how cutting the funding mechanism to solve this issue makes sense.

Mr. CUMMINGS. So just one last thing. I also listened to you as you talked about the idea that you wish you did not have to go through this. And none of us, unless we've been through it, can really put ourselves in your place. But as you were talking, I kept going back to what I said to you a little bit earlier, that is, you've taken your pain, turned it into a passion to do your purpose.

You could have easily gone—not easily, but you could have gone into a corner and just said: No, I'm not doing anything. I don't want to be bothered. I don't want to go through this. I don't want to relive it.

But you've been able to turn it around, and now I think it's something that feeds your soul. I often say that our God is a recycling God, taking the pain, quite often, recycling it so that it can become something even stronger and better.

And so I thank you, and sorry you had to go through this, but I thank you. But I also thank your son. I understand. Doctor. Thank you, Mr. Chairman.

Ms. BECKERLE. You asked earlier about what you might do differently. I just want to say: You're doing everything exactly amazingly right. We are so, so grateful for your voice, and you know, as you see, the voice—your voice is the voice of Chad, it's the voice of all children and all families that have been affected by cancer. It's the voice of everyone who's affected by cancer, and I am personally so grateful to you for your bravery, your courage, your voice, and your commitment to continuing to work toward making a difference at a time when it really, really matters, so thank you.

Ms. CARR. Thank you. And I would like to say, I think you're right. I think we've seen through this whole journey these—things come together. They've come together in a way that somehow makes sense, and I know that doesn't make sense, but when you can see the puzzle pieces coming together to do something that's beyond a single person, we're blessed to have that.

And I feel that, unfortunately, this was my role in life and that was Chad's, and his journey was to create change, and this was to be his legacy. So I'm going to continue to fight and do whatever I need to do and partner with anybody who wants to to help make that happen and make that be his legacy.

Mr. CUMMINGS. I mean, you are the agent of change.

Ms. CARR. Well, Chad is.

Mr. CUMMINGS. Well, yeah, he's working through for you.

Ms. CARR. Yeah, I'm doing my work for him.

Mr. CUMMINGS. Thank you.

Chairman CHAFFETZ. Thank you.

I now recognize the gentleman from Tennessee, Mr. Duncan.

Mr. DUNCAN. Well, thank you, Mr. Chairman, and thank you for calling this hearing.

And you know, I've been here a long time, and I've served on four different committees, and I've heard—I've been in hearings on everything that you can imagine, and I don't think I've ever heard a kinder, sweeter tribute from one witness to another than Dr. Beckerle just did for Mrs. Carr. I think that's really, really wonderful, and I can't top it.

I can tell you. I wouldn't even try. But I will say this. You know, I'm so sorry because we all have so many meetings, and I really am sorry that I couldn't get here for all of your testimony. I'm glad I've heard what I heard so far.

But I have four grown children and now nine little grandchildren, all in Knoxville, and I have—and I really, I'm wrapped up in all of them. But I've got a little grandson who's just a little bit—he turned four in February, so—and I'm really wrapped up in that little boy.

I got—Saturday, I got to go to his first tee-ball practice, and you know, I've always heard it said that the worse thing that can happen to you is to outlive one of your children, and I don't have any question about that. And it just—you know, thinking about did I understand that your little son would have been—or was 4 or so when he passed away, so I really—I'm so so sorry.

I can tell you this. Several years ago, I was the first one to cosponsor a bill to give the NIH a 100 percent increase in funding over a 5-year period. Yeah, over a 5-year period, 20 percent a year, which I wouldn't have done that for any other agency because, you know, I'm a conservative Republican. I voted to cut about everything up here.

But because, you know, we've got a \$20 trillion debt, and there was an article in the paper yesterday that said it was going to be 91 trillion by the official government estimate in 30 years. I mean, you know, if we sit around, we let that happen, we're going to destroy the country, I mean, basically. What we'll do, we'll just be printing so much money that it will just—everything—they tried that every country in the world and it hadn't worked anyplace yet.

But I can tell you I very much favor medical research, and I appreciate the work that you all are doing. I do have to say this, though. You know, everybody in the country wants us to give them money for medical research, so we've got to try to figure out as best we can on where we get the most bang for the buck or where we're making the most progress. And I'd like to know—you know, I go every year—I've gone every year for the Susan Komen Race for the Cure, you know and the women.

I say one reason I go, that's the biggest turnout of all beautiful women of thousands and thousands in Knoxville. But you know, men wouldn't turn out for run against prostate cancer the way that women turn out like that. But where are we making the most

progress or where are we getting the most bang for our buck? What would you all say about that, anybody?

Mr. JACKS. I don't think there's a simple question to that answer, Congressman. I think we're getting—

Mr. DUNCAN. I figure there wasn't a simple answer.

Mr. JACKS. Yeah.

Mr. DUNCAN. I know there's some kind of answer. We have to try to find out.

Mr. JACKS. Certainly, I think we would all agree that the investments that have been made at the NIH and the NCI have been foundational in all the progress that we've been talking about, and we have entered a new era when it comes to how we think about cancer but also how we treat the disease.

So I don't think you'll find much argument that that is very effective use of American tax dollars. The foundations that you've described, and that Mrs. Carr has started, contribute. They are a meaningful piece, but actually a relatively small piece, and so the bulk of the support that takes place in universities and government laboratories comes from the NIH, and I think the progress that we've made against cancer and other diseases really speaks for itself.

Mr. DUNCAN. Yes, ma'am.

Dr. JAFFEE. And I'll just add that Blue Ribbon Panel did identify 10 areas of priority based on all of the progress we've made so far. So in a way, that was a panel that was able to prioritize, as you're suggesting. But again, a lot of the priorities were to identify the challenges and try to overcome those challenges, so we've had some great successes.

Now we need to go the next step and address the challenges that still remain, including diseases such as pediatric cancers that we're just learning, in the past 5 or 6 years, really mechanistically are different. They're different from adult cancers, and that was an important piece of information that came from NIH funding and basic research. So I think this is a very important area.

Mr. DUNCAN. Yes.

Ms. CARR. I had also—I appreciate you saying that because that is one thing I think that, you know, the bulk of the research has been on the adult cancers and the thought being that it will trickle down. But kids are not adults. They're not getting cancer for the same reasons, so focussing more on those pediatric cancers, not that there aren't, I agree, there are some that are—there's overlap, I understand that, but these kids, kids are not adults, and the trickle up approach is where I'm thinking it might, make more sense.

Mr. DUNCAN. Well, I will tell you, my dad and one of my uncles died of prostate cancer, and now I've got a little touch of it, so I'm dealing with that. So I'm very much interested in what you all are doing, and I'll support you every way that I can.

Yes, Dr. Beckerle. I've run out of time so maybe you can—

Ms. BECKERLE. Have I run out of time?

Mr. DUNCAN. —say something quickly.

Ms. BECKERLE. Okay. Just very quickly. I think the—what you're seeing in the progress today in terms of reduction in cancer deaths and increased survivorship is the result of decades of investment



of the Federal Government in cancer research and in fundamental biomedical research.

A lot of the research that has led to the cures that we have today, and our knowledge about how to prevent cancer, has come from basic discovery science based on people following their curiosity and discovering new things about how cells work that only later did we appreciate are really critical for tackling the cancer problem.

My lab started out working on a protein in chicken gizzards, and now I'm working in Ewing's Sarcoma, so you know, just one example, but it's really the fundamental science that has led to the discoveries and the cures that we have today.

Mr. DUNCAN. All right. Thank you.

Chairman CHAFFETZ. I thank the gentleman.

I now recognize the gentlewoman from Illinois, Ms. Kelly.

Ms. KELLY. I've been on this committee for two terms, I think, and I've never felt like I feel now to run around and just give everybody a hug and say it will be okay.

But Mrs. Carr, thank you for sharing your family's story with us today, and thank you to Jason, and CJ, and Tommy for not only fighting for Chad but for fighting for all the children who can't fight for themselves.

Early on in my career, a long time ago now, I worked on PIDS, and I worked with St. Jude's patients, so I cannot relate exactly because you're a mom, but you know, I saw kids that we saved, but I went to funerals also, so thank you so much.

The role of clinical trials toward discovering life-saving medical innovations cannot be overstated. As chair of the Congressional Black Caucus, Health Braintrust, my priority focus this year is on medical research, priming the provider and researcher pipelines, and alleviating barriers, to and increasing recruitment of underrepresented communities in clinical trials.

Like you, Dr. Beckerle, I believe that research is our best defense against diseases and conditions that strip too many of our loved ones and friends of their vitality. And like you, Dr. Jaffee, I believe we have to ramp up efforts to identify culturally competent solutions to provide the medically underserved with accessible cancer treatment.

My congratulations to you and your team for reducing the access gap to cancer, clinical trials between minority and nonminority communities. Can you be more specific about which minority communities are represented in clinical trials within the 60 percent margin you mentioned?

Dr. JAFFEE. Right. So it's a good point. It's mostly African Americans from Baltimore. It has a large African-American community, but we do also have a Hispanic community, and we've also increased it in that community as well, but most of what we do is geared toward the African-American community.

Ms. KELLY. What is being done to further eradicate barriers to clinicals trials, and what can Congress do to be helpful? And I guess, because Mrs. Carr is here also, like you talked about, we need to do more around kids, but also in the minority communities also.

Dr. JAFFEE. Yeah. So I have to be honest, it was research that helped us figure things out, and you know, we were concerned that there were prior history, among African, Americans, that research was bad due to incidences that happened 20, 30, 40 years ago. But as it turns out, that wasn't the issues for our community, and it was through research that we learned that several issues were important.

One, the biology of not only the cancers are different, and we're learning that through biological studies, but also patients, African-American patients are more susceptible to high blood pressure and other diseases that would make them ineligible if our criteria in our clinical trials were not more—a little looser to allow for minimal damage to other organs. So that was a really big finding that without the research we did, we wouldn't have realized.

Another issue that's very important is that clinical trials are—do take more time, and so we had to figure out how to accommodate our patients both in transportation and also not requiring more than what they could handle with having to be at work or family members having to be at work or somebody taking care of the kids.

So there were a combination of social and medical issues that we identified.

Ms. KELLY. Do you feel like you still deal with the Tuskegee Effect—

Dr. JAFFEE. And that's what I was referring to, and actually not. Believe it or not, that was not really the issue that was raised among our patients. And in fact, the number of patients we were seeing in the African-American community was not reduced. It was the ones that we were getting on to clinical trials.

And as we've all pointed out, clinical trials are very important because most of the cancers we're dealing with are not curable, and so we wanted to make sure that African-American patients as well had access to the best clinical trials and were willing to consider them.

Ms. KELLY. Thank you. I represent the 2nd Congressional District of Illinois, and particularly, Chicago is home to two of the Nation's 47 elite NCI-designated comprehensive cancer centers, the Robert H. Lurie Comprehensive Cancer Center of Northwestern University and the University of Chicago Comprehensive Cancer Center, and I'm familiar with the work of NIH research funded cancer institutions.

However, I would like your general insight about the presence of NIH research universities that are embedded in residential and commercial districts. Can you speak to the economic activity that NIH research institutions generate both within the medical research setting and also the direct economic impact that NIH research institutions have on surrounding communities, and whoever wants to answer.

Mr. JACKS. Perhaps I'll start. I direct cancer centers, not a comprehensive cancer center. We do more basic foundational research, but we are also located nearby to the Dana-Farber/Harvard Cancer Center, so it's similar to the ones that you've mentioned in Chicago. And what we've observed is the investment from the Federal Government stimulates private investment very, very significantly.

Kendall Square, where MIT is located, used to be a very industrial area, and when I joined the MIT faculty 25 years ago, that set of industries was in decline. If you were to visit Kendall Square today, you would be amazed at the number of pharmaceutical industry, biotechnology companies, medical device companies that have now surrounded the MIT campus. Why? Because they need to be close to where the action is, and the action in our sphere is funded by government grants.

In Massachusetts alone, there was, last year, \$2 billion of inter-capital investment and the formation of new companies in this space, so that's just one indication of the economic payback that such investment makes.

Ms. KELLY. So besides saving lives and the moral compass part of it, economically, it makes sense, too.

Mr. JACKS. Most definitely.

Ms. KELLY. Thank you all.

And I yield back the balance of my time.

Chairman CHAFFETZ. Thank you.

I now recognize the gentleman from Alabama, Mr. Palmer for 5 minutes.

Mr. PALMER. Thank you, Mr. Chairman.

I want to ask a few questions, and I apologize for having to step out for a few minutes. This is something that really, really touches me.

And what I'd like to know is there—I've really been working on regulatory issues that have impacted everything in the country, and this is for our researchers. Are there any unnecessarily burdensome regulations from the FDA or other agencies that you think we could modify, change, correct so that it doesn't so restrict cancer research?

Dr. JAFFEE. So I'll give it a shot first. So I do work pretty closely with FDA. I hold investigator-initiated INDs, and I have to say that the FDA is very, very helpful. It helps us develop more rapidly drugs because of their large experience in drug development.

I think there has been reorganization recently, to your point, that has really helped by bringing cancer under one leadership. It's been very, very helpful. I think the progress we've made in cancer drug development, immunotherapy drugs being a specific area, has really helped to push the FDA to see that we need a more rapid way of getting drugs developed.

And so from my point of view, I really see the FDA as being very helpful, and the FDA has been modifying how they do business based on the changing environment.

Mr. PALMER. One of my very close friends has a brain tumor, and he's going to India for treatment. It's a treatment that's been approved for testing at Johns Hopkins for Alzheimer's but not for treatment of the tumor. It seems to be working. And one of my concerns is some of the impediments that the FDA puts there for people who want to make that choice, and rather than having to go to India, to be able to get that treatment here and give them a fighting chance, and that's one of my issues.

Another thing is, just—do you know, off the top of your head, how much at the NIH—did you want to respond to that, Mrs. Carr?

Ms. CARR. You know, I will. I would like to actually because the community that we're involved in with these families that have suffered with children with DIPG, unfortunately, at lot of times they're forced to go abroad as well.

Mr. PALMER. Yeah.

Ms. CARR. They're—you know, they're ahead of the game in Australia, in the U.K., Germany, even Mexico in some senses, and they have no choice.

Mr. PALMER. So people think when you go to India, you're going off for some exotic treatment, and he's going to Bangalore, which is like our Silicon Valley. I mean, this is very high tech, it's sophisticated, and then just from a personal perspective and I think from the perspective of a lot of patients, we need to allow that to happen here. The patient needs to have that choice. But—

Ms. CARR. Totally agree. When there's so much at risk and there's so much on the line, parents, at least, are willing to do whatever it takes.

Mr. PALMER. That's right.

Ms. CARR. And when you are telling someone there's a 0 percent chance, and someone saying, well, we have this option and would you want to try that, you know, to be able to do that is important, I think.

Mr. PALMER. Well, I appreciate you—

Ms. CARR. Hope.

Mr. PALMER. I appreciate you getting my attention and giving that response.

I'm from—I grew up in rural northwest Alabama, in the, you know, what people would consider dirt poor, and I'm particularly interested in what the Huntsmen cancer research is doing in rural areas. Is that nationwide?

Ms. BECKERLE. So actually because we are surrounded by vast rural and frontier populations, we just are in a really great place in the country to make this a focus, and we believe that the work that we're doing in Utah and in the mountain west, of course, has complete relevance to rural and frontier areas, other places.

So for example, the symptom management tool that we developed, we know that patients undergoing chemotherapy who are rural and frontier patients drive long hours away from the medical center after their treatment and they go back home and they are facing, you know, debilitating, sometimes, challenging side effects. And so we developed a tool that touches base with them on a regular basis and with their caregiver, and we found that that has really alleviated their symptoms quite dramatically and also reduced caregiver anxiety.

So that kind of thing is a way in which we reach out and try and support our rural and frontier patients and their families during the course of their treatment. And what we're learning in Utah should be relevant around the country.

Mr. PALMER. If the chairman would indulge me one more question. It's an issue that this committee has really been focused on, particularly the chairman and Ranking Member Cummings, and that is drug prices.

And I saw a study here from Memorial Sloan Kettering Cancer Center, about \$3 billion wasted in cancer treatment where the drug

companies are putting more medicine in the vial than they need, knowing that it's more than is needed for the treatment, and that medicine is basically being thrown away, and valued at about \$3 billion.

Would any of you like to comment on that? Are you aware of that? Is that something you're aware of?

Mr. JACKS. No.

Mr. PALMER. I would recommend it was—I've got the article here. We can—if I may, we'll enter it into the record.

Chairman CHAFFETZ. Without objection, so ordered.

Mr. PALMER. With that, Mr. Chairman, I'll yield back.

Chairman CHAFFETZ. I thank the gentleman.

I now recognize the gentlewoman from Florida, Mrs. Demings for 5 minutes.

Mrs. DEMINGS. Thank you so much, Mr. Chairman, and to our ranking member.

And Mrs. Carr, thank you so much for talking about Chad. I didn't know Chad, but I raised three sons, and I know Chad, and to hear your description of him, he represents thousands of children throughout this country, millions throughout the world.

And in your written testimony, you talked about the DIPG claims about 300 lives a year, and you mention that that's really not a large or huge number, but which child would we not do everything in our power to save? If there was one child, two, or 300, which one would we not do everything within our power to save?

I also understand that ChadTough Foundation is part of a larger group of organizations looking for clues to DIPG. Together, these groups are funding a registry to collect information on the disease. Is that correct?

Ms. CARR. Yes. The DIPG collaborative that I spoke about before has formed the DIPG registry. So when Chad passed away, we donated his tumor postmortem, and it was the University of Michigan has some of that as well as a physician who is now going to Lurie Children's Hospital, and then it is also kept in the registry so it can be utilized by scientists around the country.

So that is one investment that this collaborative has made to really get the word out that this is a way that we can impact research however.

Mrs. DEMINGS. Last month, NIH announced that it was launching its largest study of African-American cancer survivors in the United States, drawing on an existing population base cancer registry, the Detroit research on cancer survivor study would look at factors that affect survivor rates among African Americans diagnosed with cancer.

I know we talked a little bit about that, but Dr. Jaffee, could you explain the range of social and biographical variables that the study might consider as it relates to cancer survival?

Dr. JAFFEE. Wow, that's a good question, and it's not my area of expertise, per se, but I would expect that there are going to be a range of issues, including what the underlying types of diseases the patients have had and what kind of access they've had for those treatments because when a patient who's healthy gets cancer, it's a lot easier to receive the treatments we have than patients who have other underlying comorbidities, so I would think that that

would be a major issue, depending on how much access to good care the patients have had prior to developing the cancer.

And then socioeconomic is important because getting access, even through transportation, to the right places is a very challenging issue for patients who don't have the means.

Mrs. DEMINGS. Thank you.

Dr. JAFFEE. I don't know if my other colleagues would like to add to that.

Ms. BECKERLE. I would just comment that I think this is one of the things that's so important about the National Cancer Institute's efforts in that the NCI can really bring together these nationwide consortia and registries so we can get information about survivorship and outcomes for patients across the entire country, and that eliminates the kind of sampling error that can happen if you're just looking at one site in one State that might be different than what happens in another place in the country. So this is a really important contribution of the National Cancer Institute to our national health.

Mrs. DEMINGS. Great. Thank you. Using data from the NCI childhood cancer study recently published, our research revealed a reduction of second malignancies among survivors of childhood cancer. Using population data, researchers were able to determine that over the course of 15 years or more, children treated with lower doses of radiation were less likely to develop second cancers.

Can you comment on the value of this sort of long-term research, any of—or yes.

Mr. JACKS. I'm happy to comment on that. I think what that study points out is progress that we've made in understanding the consequences of the treatments that we use, and radiation is a good example. It's now clear that radiation can promote the kind of changes in cells that ultimately lead to cancer, and so, therefore, those treatments have to be used at appropriate doses and minimized wherever possible. Fortunately, that progress is being made and it's playing out in now in the observation that there are fewer second malignancies in those children.

Mrs. DEMINGS. Great. Thank you. Doctor.

Ms. BECKERLE. Yeah, I think just related to that. I think this area of childhood cancer survivorship is really, really important. We have this great success now in our ability to treat childhood cancers, even though we have a lot more to do. But what we're now beginning to see is that there are what we call late effects of these treatments. Sometimes due to the radiation or chemotherapy, sometimes psychosocial effects, fertility effects, et cetera, and so there are many, many things where research is required and will be really helpful to address the current unmet needs of individuals who have undergone a successful treatment for childhood cancer so that we can make it better going into the future.

Mrs. DEMINGS. Great. Thank you so very much.

Mr. Chairman, I yield back.

Chairman CHAFFETZ. I thank the gentlewoman.

We'll now yield to the—or now recognize the gentleman from Iowa, Mr. Blum for 5 minutes.

Mr. BLUM. Thank you, Mr. Chairman, thank you to our panelists today for being here, and thank you for your emotional testimony,

Mrs. Carr. I was standing in the doorway when you started to testify, and I'm the father of six children, and I started thinking about every one of them, and I can't imagine what that was like, and I am so proud that you're here today, and you've served the cause well, and I'm sure Chad is very proud of his mom today as well.

Ms. CARR. Thank you very much.

Mr. BLUM. Thank you so much for being here.

Ms. CARR. Thank you.

Mr. BLUM. I have two questions. First of all, there's—we look at the dollars spent by governments and by people who donate and contribute to research, cancer research, Alzheimer's research, whatever it may be, and I'm always concerned, as a career businessman, what kind of collaboration is there between the disparate research facilities and institutions? Are we doing enough to share the information? There's—collectively, there's not enough, trust me, there's not enough research going on. I'm a huge advocate for what you want, huge.

But there's a fair amount going on, billions of dollars being spent, and I want to make sure that we're sharing that information between all of the researchers, so maybe people involved in research facilities could—could you give me your thoughts? Is there enough collaboration? If there's not, can the Federal Government play a role in that like a repository of information or—

Mr. JACKS. If I could begin. You raised an important point actually, and I think we're facing that problem increasingly by the day because the amount of data that we're generating today is greater and greater, you know, because of new technology. So the answer is yes, there is considerable collaboration an interaction. The National Cancer Institute, cancer centers program, would be one example, a network of cancer centers throughout the country who interact and share information, but there's still a gap.

And in fact, the Cancer Moonshot Blue Ribbon Panel recommended the development of a national infrastructure to facilitate the sharing of cancer data, to store it more appropriately, to make access easier, to develop the kind of software tools necessary to analyze it so as to break down any existing barriers that do currently exist to improve that situation.

So there's examples of progress, but there's actually still a need, so I think the Moonshot funding that you have funded will help us close that gap.

Dr. JAFFEE. And I could give you a few examples of what's already ongoing. So we now have, through the NCI's efforts, the development of an open access resource for sharing cancer data view, the Genomic Data Commons, and they've even brought in outside groups, such as Foundation Medicine, which is going to double the total number of patients' information into this, and this is an open access available to everyone.

And again, as Dr. Jacks said, one of the Blue Ribbon Panel initiatives is to start to increase this and use the funding that was given to us from Congress to now increase this ability.

Also, the NCI is developing genomic cloud pilots, and these pilots will again expand data sets that will include imaging, will include proteomics, immunotherapeutics. So integrating all these data sets so that we can really start to look at different cancers and better

understand the whole tumor microenvironment and not just the genetics because there's other factors that contribute to it.

In addition, what it would allow us to do is to look at rare cancers and try to use now cancers that have been put into this database, it will increase the number. We can now make more hypothesis of why patients get these cancers and identify targets to develop drugs against.

Ms. BECKERLE. Well, all of us who are in the cancer research community are desperately working to improve outcomes for cancer patients, and we know that none of us as individuals or even with our institutions hold all of the knowledge that's necessary. So we are naturally inclined to collaborate and to share information.

And the National Cancer Institute is really helping to support us in that effort. An example that I would give that's related to our new knowledge and the precision medicine era is that we now are trying to test really exciting new therapies that are only relevant for a small subset of patients that have a particular genomic signature, particular DNA signature. And so what that means is that even for a disease like, you know, lung cancer that is a relatively common disease, the patients with a particular type of lung cancer that might be eligible to contribute and to participate on a particular clinical trial might represent less than 10 percent, even 1 percent sometimes, of the total patients.

So the only way we're going to really understand whether that treatment is going to work is if we have a national network in which we find these patients across the entire country and bring them together to participate in a clinical trial, and that's exactly the kind of infrastructure and support that is provided through Federal funding by the National Cancer Institute.

Mr. BLUM. My time is expired, but I would just like to say there's a lot of things—I'm Republican, a lot of things government shouldn't be involved in that we're involved in, but one of the things that we should be involved in is researching these hideous diseases, and I was for the 21st Century Cures Act, and I stand against the President's proposed budget cuts, and we need to be spending a lot more, not less, in these areas.

And I thank you very much, and God bless you, Mrs. Carr.

I yield back my time

Chairman CHAFFETZ. I thank the gentleman. I now recognize Mrs. Watson Coleman from New Jersey.

I guess we're going to go to Mrs. Lawrence from Michigan.

Mrs. LAWRENCE. Thank you, Mr. Chair. I want to acknowledge Mrs. Carr and express my deep condolences for the loss of your son. Being from Michigan, we watched the love, the support, and your advocacy, and just know that as a Michigander, Chad's inspirational fight against cancer and your devotion to raising funds and awareness for DIPG is remarkable.

Ms. CARR. Thank you very much.

Mrs. LAWRENCE. I am so proud of you. Not unlike political parties, Michigan State and the U of M fans don't often agree on everything, however Chad's battle with cancer and your commitment to his continuing legacy has crossed across the fan lines and united Spartans and Wolverines behind a common cause.



Cancer research is something that impacts all of us, not just Democrats or Republicans. When the President released his proposed budget, I was devastated to see the Draconian cuts being made to NIH. In your testimony, you discuss the major strides that NIH researchers have made toward cancer such as leukemia. As you noted, 40 years ago leukemia had a 10 percent survival rate. Today, the survival rate is almost 90 percent. That represents just one of the countless medical achievements that has been made as a result of funding to NIH.

Mrs. Carr, as someone with firsthand knowledge, I would like to give you an opportunity to speak to us as Members of Congress, who have the ability to increase funding to NIH, to discuss the merits of research being done by the funding.

Mrs. CARR. Thank you. We like to call it, in the DIPG community, what we hope for is the homerun strategy.

Mrs. LAWRENCE. Okay.

Mrs. CARR. You know, pediatric leukemia was considered a rare disease not too long ago. They focused, and I think, you know, whether or not you consider DIPG, it's rare, I mean, there's no doubt, but brain tumors in general are not rare. Pediatric brain tumors are the leading cause of cancer death in children. So focussing on pediatric brain tumors is something that makes sense.

And for us, the strategy that we're taking and as far as our funding goes, which again is a drop in the bucket, is that if we focus on the hardest tumor and really focus on it and now with the momentum that they are—you know, they are able—there's tissue now. They can study the samples. There—the CED and learning about the ability to pass the blood brain barrier with a catheter, which was the clinical trial that Chad was a part of, if we really focused, I feel like, you know, even raising the bar from 0 percent to 2 percent is a movement in the right direction.

And we've seen just at Michigan alone, a lot of researchers that are now—because we're willing to provide some funding, and there's big room to increase success rates there, that they're looking—you know, young scientists are now interested in looking into this disease, and that's a really wonderful thing.

You know, we talked about clinical trials being important. A lot of children with DIPG, Chad was one of the lucky ones that was able to participate in a clinical trial. A lot of these children, they don't meet the requirements, and they aren't even able to participate. And as a parent, I can tell you one thing, when you're basically deciding on a treatment plan for your child, because that's what this is, the doctors don't know what to tell you. Radiation is the only thing that they know to tell you, which we know now causes secondary problems.

So in the end, if they were to survive, they're not, you know, they're not out of the woods. They're going to be other secondary cancers, most likely. I mean, Chad received 30 rounds of radiation.

So I think the way we're looking at it is focussing on the toughest, allowing that to open the floodgates for the other more treatable tumors, and really focussing on those pediatric tumors because, again, children are not adults.

Mrs. LAWRENCE. I want to thank you again and commend your commitment to fighting, and again to say I hope my colleagues are

able to take your story as a reason for why we cannot allow these proposed cuts to NIH to be implemented in the upcoming budget.

And just on a personal note. Everyone strives to have their life to be a legacy or to leave their mark or to do something that will be reflected in history as a game changer. Your son did that.

Ms. CARR. Thank you.

Mrs. LAWRENCE. And with your fight, his life has—will mean so much more to so many people, so thank you so much.

Ms. CARR. Thank you. We really believe that his 5 years, he's accomplished more than most people—

Mrs. LAWRENCE. Yes.

Ms. CARR. —accomplish in their whole lives.

Mrs. LAWRENCE. Thank you so much.

Chairman CHAFFETZ. Thank you.

We'll now recognize the gentleman from Wisconsin, Mr. Grothman for 5 minutes.

Mr. GROTHMAN. Sure. Just a general question. What are the funding requirements for 21st Century Cures and NIH's work in cancer research?

Mr. JACKS. What are the funding requirements?

Mr. GROTHMAN. Yeah.

Mr. JACKS. Are you talking about the nature of the applications or that sort of thing?

Mr. GROTHMAN. No. How much do you anticipate—

Mr. JACKS. Oh, I see.

Mr. GROTHMAN. Yeah.

Mr. JACKS. Well, we outlined several recommendations, each of which has a pretty broad scope. Frankly, the monies that came through the 21st Century Cures Act are a start to begin to accomplish those goals, but I don't think we can accomplish all of them with the monies allocated, but it will certainly be a helpful start.

Mr. GROTHMAN. Can you give me the dollars numbers that think?

Mr. JACKS. Well, the current allocation for this year is 300 million. I think it could have been easily two or three times that amount, and we could have spent the money wisely.

Mr. GROTHMAN. Okay. Is there any way you can prioritize research better that you can shave that down at all? I guess you're telling me no.

Mr. JACKS. Well, within that specific program, we worked very, very hard in this Blue Ribbon Panel to create a series of prioritized recommendations. So I think what you've got there is our best effort in a particular form of cancer research, a more mission-focused form of cancer research. So that is our set of priorities for that particular program.

I should add, that funding, in our view, does not in any way replace the standard appropriation to the NIH or the NCI, which is much more substantial and provides funding across a wide range of areas of discovery research.

Mr. GROTHMAN. I understand a lot of what 21st Century Cures did is very necessary. I'm about the cheapest guy up here, and I've ordered for it because I do know how important, not just research as for cancer but other things as well, and all the people affected by them.

We just touched upon brain tumors in children. Do you know how many different institutions around the country are maybe doing work in this area?

Mr. JACKS. Mrs. Carr may know better.

Ms. CARR. I'm not really sure how many are focussing. I think I know, again, at Michigan we are trying to create a brain tumor center where that's what they focus on, so I don't believe anything exists like that currently, not that there are people doing research all over. And as far as DIPG, that brain tumor, there is several. There is some very phenomenal researchers at Stanford and Sloan Kettering and SickKids in Toronto.

Mr. GROTHMAN. Right. I guess what I'm trying to get to is, cancer in general—or maybe I'll give you this question in general. I know we do a lot of research in Wisconsin, a huge amount of research on cancer in Wisconsin and have been doing it for many years.

If I just asked you in general how many different universities around the country are doing cancer research, would you be able to answer that for me.

Mr. JACKS. I would say, of the research universities in America, all of them have programs that relate to cancer. The McArdle Cancer Center from Wisconsin is one of the leading ones, and that kind of broad-based effort is, frankly, necessary for a variety of reasons. One, there is a lot to be learned, and we want to draw on the resources across the country. And, two, you actually want to train the individuals in your States to become biomedical researchers and scientists. And so that has to be done on a national level as well.

Mr. GROTHMAN. I guess what I'm getting at is you have two competing interests here, in my mind. On the one hand, it's good that you have a lot of institutions around the country doing cancer research because maybe there's something that people at MIT think are going to work that other people think would never work. And if you had a top-down approach, they would say "don't go there," but you're able to go there and find good things. On the other hand, you have a concern that, if there are many places around the country, you may be duplicating efforts. You may not be coordinating with each other.

And that's what I'm getting to. If there are—you tell me—40, 50, 60 different places around the country doing cancer research—maybe there aren't. I don't know. Maybe there are 20. Maybe there are 80. That's why I asked you. Are we—where do you think we are in that conflict or competing goals? You know, make sure that everybody is independent and can do something if it's against conventional wisdom, but on the other hand, you don't want to have four people doing the same thing or somebody doing research that they found out in another place around the country is not effective 5 years ago.

Dr. JAFFEE. I think that's a really complex question. It's a really important one. It's just really complex to give you a straight answer, but I think there are a couple of facts that we do know. And that is if you look around the country at the different cancer centers, there's different expertise at different cancer centers. So, as you point out, how many places do brain cancer? Not that many.

And it's also geared toward what funding is available. So, currently, the funding is pretty tight at the NIH and the NCI. We used to get about 25 to 30 percent of grants funded. Now we're down to between 10 and 14 percent. That limits what can be done. We believe, based on review groups, that there's much greater amounts of good research than that's being funded. So I suspect that the review process is one way to prevent duplication.

Mr. GROTHMAN. It just scares me like when you say you're not sure how many places around the country are doing research on brain tumors and young kids. And I would have thought people in your position would say, "Oh, yeah, we're doing it at UCLA, and we're doing it in Georgia, and we're doing it in Wisconsin, and we're doing it in Michigan." But you don't know, do you?

Dr. JAFFEE. Well, because there aren't many places that do it. That's the problem. Like if you ask me about immunotherapy, I could tell you there are five places that do immunotherapy around the country in a big way. But I can't tell you about brain tumors because I can't, other than thinking, well, St. Jude's probably does some brain tumors because they're a pediatric, but there's no brain tumor institute.

Ms. CARR. And that's really what we have been trying to focus on doing. And when you talk about DIPG—and it's, again, a small, rare tumor—the folks that come together to fund that effort, that's what we do as a collaborative. We make sure that every proposal that comes through because there's so few of us, and there's so little money there, that we don't—the duplication of efforts, that's something that we don't want to see happen.

Mr. GROTHMAN. It just concerns me that you don't know. And like I said, I would think you would show up here and at least one of you, and maybe there is somebody else who wasn't invited here today, but somebody would say, "We are doing cancer research in these 80 institutions, and these are the specialties of the 80 institutions," and just have it here.

Mr. JACKS. It's probably important for you to know whom you're speaking with. We represent particular institutions. If you were to ask the director of the National Cancer Institute, I think he would have an answer for you. And sometimes it's difficult to know in the sense—for example, at MIT, last year, we announced a new initiative on pediatric brain cancers. Now, my colleagues probably don't know that because it was a local effort.

Mr. GROTHMAN. But they should know it, right?

Chairman CHAFFETZ. The gentleman's time has expired.

I will now recognize the gentleman from California, Mr. DeSaulnier.

Mr. DESAULNIER. Thank you, Mr. Chairman.

I just want to really thank you and the ranking member and all of the panelists. This is a personal issue for so many of us, and I'll explain that a little bit, but I want to address a comment from one of my colleagues from the other side of the aisle about cost-benefits. As a Democrat from the San Francisco Bay Area, I think cost-benefits are important. Last hearing of this committee I believe last week talked about the Department of Defense and an audit by the business community and McKinsey that there is \$125 million worth of waste in their budget. Yet the administration is sug-

gesting taking money away from NIH to put in their budget. So, before we do that—and by the way, that hearing was bipartisan, as this one is, in terms of applying our oversight and making sure we get the best return for investment for taxpayers in the Department of Defense. But to jump to the conclusion that we should give them money at the expense of NIH I just find appalling.

And on that level, just the cost-benefit, every dollar invested in NIH returns almost \$8.50 in extra spending. Just on the genome project, it has resulted in nearly a trillion dollars of economic growth. All of these things I learned because, when I was elected to Congress 3 years ago, I unfortunately joined the club. Fortunately, what I have is chronic lymphocytic leukemia. And during the process, there were ups and downs as to my mortality, but as has been testified earlier, 20 years ago, there was a 10-percent survival rating. Now there is a 90-percent survival rating. So, having been involved in this and absorbed myself in the history and having now talk to Dr. Mukherjee and Dr. DeVita and read their books and gone to NIH and spent multiple times at the University of California at San Francisco, which we proudly say in the Bay Area say is the second largest recipient of NIH funding, and we're hoping to surpass Johns Hopkins at some point, and then spending time at Stanford and my local hospitals, it's really remarkable—and a lot of this goes to the survivors, the family members, who have found their voice and the voice that you have expressed today.

I mean, your son clearly is here in our presence today, and you know that, but it's not a trite thing to say that your experience. So, in my case, reading back, Sidney Farber, having grown up in Boston, having looked at the Jimmy Fund advertisement at Fenway Park as a young person and now, never knowing what that was about, and now knowing that that was both an initiative by people who cared to come in front of Congress and convince Congress and President Nixon to sign the legislation that helped start all of this. So the synergy, but then understanding that—and I'm cautioned by people in my own district, "don't get carried away"; "there's no cure." For instance, in my instance, people at NIH, wonderful researchers, you go out there, and it's hard to believe the value we get, and I know Mr. Raskin will speak since he represents that area. These young nameless people who are heroes who have saved my life and millions of other people's lives.

So, in that context—and then seeing what this brings in value added around the world. They showed me a map of all the affiliated relationships they have around the world. It's like a military map. And the moral high ground that we get as Americans by doing that and speaking to the chief researcher out there and how many times he's been to China because China is trying desperately to replicate what we have here, it's just staggering to me that we would consider—and it's a real statement of our values to how we invest.

I think one of the most amazing statistics is, research-related gains in average life expectancy of the period from 1970 to 2000 have an economic value in the United States of \$95 trillion, and maybe not in this instance, but I'm a living example of that. So my oncologist told me that, 15 years ago, if someone was diagnosed with what I had, he would sprinkle some water on me and tell me

to go enjoy as much of my life as is left. Now, as has been said, I hopefully will have an 85-percent survival rating. But a lot of that, back to pediatric research, we know that Dana-Farber was because people, when you read the stories of young people dying of leukemia and what I have, it was because the moral obligation for Americans was to invest in that.

So, just briefly, in conclusion, one of the things that I've tried to work on and starting a Survivors Caucus, which I hope as many Members join as possible—and it's very broadly defined—is talking to Dr. Mukherjee and Dr. DeVita, and I hope they will come to speak to this group, and I hope you will come as well. One of the things has been communication. We do a bad job of communicating the amazing return on investment. And then the communication from the medical industry to people who have been impacted by this.

So Mrs. Carr, you are an example of that voice. How can we do better?

Ms. CARR. I think listening is part of it too. I mean, I think hearing what families have to say, hearing about these experiences and really listening and thinking about, how can I help make that change? How can I help do something? You guys are in the position to actually make that happen. I mean, we can talk to you all we want, but people in these rooms are the ones that—are the ones that can make things happen. So, I mean, for me, that's what I would say. You guys hold all the power.

Mr. DESAULNIER. Well, we can't do that without your voice.

So thank you, Mr. Chairman.

Chairman CHAFFETZ. Thank you.

We'll now recognize the gentleman from Maryland, Mr. Raskin, for 5 minutes.

Mr. RASKIN. Mr. Chairman, thank you very much.

I am, indeed, the Congressman from NIH, from the Eighth Congressional District in Maryland, and the NIH is very much in the heart of my district. And being the Representative from this area, I know intimately, and I keep close track of all of the research that's going on into leukemia, lung cancer, colon cancer, cystic fibrosis, asthma, bulimia, drug abuse, alcohol abuse. I mean, it's just extraordinary the range of scientific inquiries and endeavors that are taking place at the NIH.

But I also want to speak as a survivor, and I wasn't aware of a Survivors Caucus, but I would be delighted to join you, Mr. DeSaulnier, in that. I had colon cancer back in 2010. I was then teaching at American University Law School, and I was a State senator.

But I read an essay by Susan Sontag in which she said something that was very poignant, which is that everybody is born with two passports, a passport to the land of the living and the healthy and a passport to the land of the sick. And all of us are going to have to use both passports at some point in our lives. What's striking to me, though, is that those people who have gone through it or have had an immediate family member go through it, look at something like a proposed \$6 billion cut in NIH medical research budget and are horrified by it, I mean, are just astounded. And

then people who have not been directly touched go about their business.

So my question for you, Mrs. Carr, and thank you for your wonderful testimony, is basically how do we maintain the consciousness of both passports and the coexistence of these two lands? I remember when my chemo ended, the very last one, feeling as if I had suddenly returned to a place from a very long, harrowing trip that I had been on. But how do we make that consciousness permeate the country?

Ms. CARR. I think it's hard. I mean, I can tell you, I didn't know a lot of these things before I had to know them. I didn't know that pediatrics only received 4 percent funding. I didn't even know what DIPG was. So I think having more people who have been there trying to resonate their experience to those and hopefully people hear, and they feel sad and they feel sorry, but hopefully they really think about that impact. And I think having these three here talking about, you know, there are benefits to research beyond just saving people right now. These are huge financial implications, and there's so much there. I don't want—I tell people, you don't get it until you get it. Unfortunately, though, I don't want people to join that club.

So I think as many advocates as we can build for helping to share our story, because, again, there are only so many of us, thank goodness, that have lost children and only so many of those that actually want to share their story. So creating more advocates amongst people in this room who can then do that and help us in those efforts.

Mr. RASKIN. Yeah. Let me ask a question of Dr. Beckerle. One of our great American aphorisms—I think it's attributed to Ben Franklin—is that an ounce of prevention is worth a pound of cure. I know—I gave a little speech yesterday about Alzheimer's disease and did some research and found that we spend 250 times more treating people with Alzheimer's disease through Medicare and Medicaid alone than we do on researching to get a cure for Alzheimer's, which is now beginning to spiral out of control. I mean, the jumps in the number of people who are suffering from Alzheimer's and are going to die from Alzheimer's are extraordinary.

So talk, if you would, about how we get people focused on prevention rather than just spending a lot of money after the fact trying to mop up?

Ms. BECKERLE. Yeah, I think this is a really important point, and I think the time is right to begin to really focus on this area. Clearly, we need to continue our investments in the development of new treatments for people who are already affected by cancer, but we now know that probably about 50 percent of all cancers could be prevented. And this is by cessation of smoking in some cases and also understanding of inherited risk and screening and early detection that can either improve cancer outcomes or prevent the disease. I think you're absolutely right. I think we now have enough scientific knowledge that it is time to really put some dedicated focus on cancer prevention.

One of the areas of the Blue Ribbon Panel was a focus on what we call precision prevention and capitalizing on our deep knowledge about cancers that run in families. We know that there are

at least 50 different types of inherited cancer, and if we could identify everybody in the country that had that inherited predisposition and screen those folks, we might be able to prevent them from developing untreatable disease.

In the case of Lynch syndrome, which we have heard about from Stefanie—Stefanie, right? Okay. Good. We know that there are about a million people in the United States that have Lynch syndrome, which causes a predisposition to colorectal cancer, uterine cancer, and a number of other cancers. Only about 5 percent of the people who have that syndrome know they have it. So what that means for them is they are doing the right thing going and getting a colonoscopy at age 50, but because they have Lynch syndrome, they are developing colon cancer way before they are starting their screening. So, if we know who is at risk, we can prevent those cancers from developing in the first place. Save lives. Save money.

Mr. RASKIN. Thank you.

I yield back, Mr. Chairman.

Chairman CHAFFETZ. Thank you.

I will now recognize Ms. Watson Coleman from New Jersey.

Mrs. WATSON COLEMAN. Thank you, Mr. Chairman, for calling this hearing.

Cancer is a very, very personal thing for me. In 1983, my mother was diagnosed with lung cancer, and the doctor told us that it did not respond to chemotherapy, nor was it operable. So we actually were very fortunate to get her into a protocol in Johns Hopkins. We lost my mother to that cancer within the 6 months period of time that the doctor said it was going to happen. But, nonetheless, we had some hope during that period of time because we knew that we were actively engaged in some cutting-edge monoclonal antibodies, immunotherapy, that kind of thing.

I lost my father to renal cell carcinoma. I have a niece now that's living with thyroid cancer. I lost cousins to other lung cancers and leukemia. So there is no sort of group of diseases that upset me more than cancer. And I think that, while we're talking about how to get out the word, how important this is, I don't think that there's a family in this country who is not personally touched by cancer, whether it's pediatric cancer—and Mrs. Carr, God bless you for using your tragedy to save so many more lives. You are such a courageous woman—but just all the different cancers.

So I think that this budget is really very—no one thought through this issue. I don't think anyone is going to support, even in Congress, taking money away from the National Institutes of Health. But it's more than cancer. I mean, it's diabetic. I'm diabetic. I certainly would like not to be on the kind of medication I am on. There are so many things that are happening that could possibly impact me even as an adult, let alone—there are so many things that affect me as an African American differently or as a person who has even more than just African blood. I got a whole bunch of stuff happening here that I might need some very specific scientific understanding, evaluation, to get at a person like me, and I represent a good number of people in this country.

So I just want you to know that I will fight as hard as I can to make sure that we don't lose money, that we, in fact, look at what is realistic in terms of our needs. There is no greater set of diseases



to conquer than cancer, and so I thank you, Mr. Chairman, for calling this hearing and giving me an opportunity to speak.

Chairman CHAFFETZ. Thank you.

Thank you. We're at the conclusion here, and I want to, first of all, thank Dr. Jacks, Dr. Jaffee, Dr. Beckerle. You do some very rewarding work, work that affects every single American. To those that you work with, you represent big institutions with lots and lots of people who work hard every day behind the scenes. They don't necessarily get the spotlight that they deserve. I hope in some small way this committee hearing will do some of that. But I hope you carry back to them how much we appreciate the work they do and how important it is. And sometimes it takes years, weeks, decades, to find that breakthrough that may have come from something we didn't think it was going to come from. If it was easy, I'm sure you would have already solved it.

So you're tackling some of the most difficult things that face our Nation. And we do have a duty and an obligation to not only hear the stories and listen, but also to fund it. And we are in a position to make a difference, and that's why I called this hearing. I think what the President's budget proposal was is an embarrassment, and it's not something I could support, certainly that aspect of it. And I do hope that, on both sides of the aisle, you will see us come together and have a very different outcome than what was proposed out of the White House.

Nevertheless, there are things that we need to continue to learn. It is the committee's intention to have another hearing. It will probably take a few months to put together, but we would like to hear from very specific scientists talk about some of the most promising efforts. I think if Members were to hear, not only the stories of the families that are affected by this, but also very specific cases—I've heard some amazing stories. Every once in a while, you'll turn on everything from "60 Minutes" to something else, and there's a big breakthrough that's right on the verge and may be happening. We would also like to hear those stories. I think that would help Members get a better grip. It is a big issue, and you've helped illuminate that, but help us think through—and I think we can also highlight the specific scientists and allow them to tell their story and answer questions because I think you get a lot more people who will then want to fund that type of research because it is so promising. So if you can help us identify that.

To Stefanie, thank you for being here. I appreciate it. I'm very glad that you came, and we wish you obviously nothing but the best.

To CJ and Tommy, pretty boring, huh? Yeah, I would agree with you. But very important stuff, and I think, later on in life, you'll recognize and say, "Wow, my mom did that?" It's not something she probably ever dreamed of. Nobody wants to come testify before Congress, believe me. But to your mom and dad, thanks for their strength and sharing your story, and it is impactful, and we do appreciate it.

And, obviously, ChadTough, we, again, wish you had never had to go through that, but you have exemplified what I'm guessing are—I don't know how to quantify it—thousands, hundreds of thousands, millions—I don't know how to quantify it—of people and

families who have gone through some things too and would probably—you go to places you don't want to go, right? You don't want to be a part of that club, as you said, but they also step up to the line, and they come, and they do it, and they do those hard things, and so we thank you for doing that, and we appreciate you doing that and wish your—you've got a beautiful family. So thanks for sharing that, and God bless you.

The committee stands adjourned. Thank you.

[Whereupon, at 11:51 a.m., the committee was adjourned.]

