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3 LEGISLATIVE HEARING ON H.R. 1740, THE BREAST CANCER EDUCATION

4 AND AWARENESS REQUIRES LEARNING YOUNG ACT OF 2009;

5 H.R. 1691, THE BREAST CANCER PATIENT PROTECTION ACT OF 2009;

6 H.R. 2279, THE ELIMINATING DISPARITIES IN BREAST CANCER

7 TREATMENT ACT OF 2009; AND

8 H.R. 995, THE MAMMOGRAM AND MRI AVAILABILITY ACT OF 2009

9 WEDNESDAY, OCTOBER 7, 2009

10 House of Representatives,

11 Subcommittee on Health

12 Committee on Energy and Commerce

13 Washington, D.C.

14 The Subcommittee met, pursuant to call, at 11:47 a.m.,  
15 in Room 2123 of the Rayburn House Office Building, Hon. Frank  
16 Pallone, Jr. [Chairman of the Subcommittee] presiding.

17 Members present: Representatives Pallone, Dingell,  
18 DeGette, Schakowsky, Baldwin, Matheson, Harman, Barrow,

19 Christensen, Castor, Sarbanes, Space, Sutton, Braley, Deal,  
20 Whitfield, Shimkus, Blunt, Pitts, Wilkins Myrick, Burgess,  
21 Blackburn, Gingrey and Barton (ex officio).

22         Staff present: Sarah Despres, Counsel; Anne Morris,  
23 Professional Staff; Elana Leventhal, Policy Advisor, Alvin  
24 Banks, Special Assistant; Allison Corr, Special Assistant;  
25 Aarti Shah, Counsel; and Chad Grant, Legislative Analyst.

|  
26           Mr. {Pallone.} We will start the hearing, and I do  
27 apologize for the delay.

28           Today the Subcommittee is meeting to review four bills  
29 relating to breast cancer: H.R. 995, the Mammogram and MRI  
30 Availability Act of 2009, sponsored by Congressman Nadler of  
31 New York; H.R. 1691, the Breast Cancer Patient Protection Act  
32 of 2009, sponsored by Ms. DeLauro of Connecticut; H.R. 1740,  
33 the Breast Cancer Education and Awareness Requires Learning  
34 Young Act of 2009 by Congressman Wasserman Schultz from  
35 Florida; and H.R. 2279, the Eliminating Disparities in Breast  
36 Cancer Treatment Act of 2009 sponsored by our own Member,  
37 Congresswoman Castor also from Florida. And I want to thank  
38 all the sponsors of these bills for the hard work on raising  
39 awareness about these very important issues, and I should  
40 also point out that they have been spending some time over  
41 the last 6 months trying to have this Subcommittee have this  
42 hearing and the reason for the delay was of course we were  
43 dealing with health care reform.

44           Now, aside from the non-melanoma skin cancer, breast  
45 cancer is the most commonly diagnosed cancer in women. The  
46 NIH estimates that over 190,000 new cases of breast cancer  
47 will be diagnosed in women in 2009, and though we have seen  
48 breast cancer death rates decline since 1990, still

49 approximately 40,000 women will succumb to the disease this  
50 year. And that is the work of advocacy groups and the key  
51 sponsors of the bills today is so crucially important. We  
52 have made great strides in detecting and treating breast  
53 cancer but there is still much more to be done and much more  
54 to learn.

55         Although all of these bills address concerns related to  
56 breast cancer, they all focus on different aspects of the  
57 disease from screening and early detection to treatment and  
58 quality improvement, and all they all raise very important  
59 issues with respect to how breast cancer patients or any  
60 other patients for that matter are being treated in the  
61 medical environment we live in today. Not every American has  
62 access to good preventive services. Not every American has  
63 the good fortune to have an insurance plan that covers the  
64 medical care they need, and that is why we are working hard  
65 trying to pass health reform legislation that will improve  
66 access to quality and affordable health care for every  
67 American. If enacted, health care reform legislation will  
68 dramatically improve our efforts in the battle against breast  
69 cancer.

70         Particularly important are the insurance reforms. In  
71 drafting America's Affordable Health Choices Act, we took the  
72 same tack as Ms. DeLauro did in taking decision-making

73 authority out of the hands of health insurers and putting it  
74 back in the hands of patients and their doctors where it  
75 belongs. In addition, the subsidies offered in the exchange  
76 and expansion of the Medicaid program under health care  
77 reform will cover childless adults and mean that many low-  
78 and middle-income women who might not have access to health  
79 insurance today will be covered in the future for the first  
80 time, and that means they will be able to access a doctor and  
81 receive treatment when they need it.

82 A key component to winning the battle against breast  
83 cancer is effective and appropriate screening, which both Ms.  
84 Wasserman Schultz and Mr. Nadler's bill seek to address.  
85 Early detection of breast cancer has long been acknowledged  
86 as an effective way to improve outcomes. In fact, studies  
87 have shown that the 5-year survival rate in women who have  
88 received timely treatment due to early detection is at 98  
89 percent, and that is why the U.S. Preventative Services  
90 Taskforce has recommended that all women over the age of 40  
91 have a mammography screening every 1 or 2 years. Now, I  
92 agree with my colleagues that early detection and prevention  
93 is key to survival, and that is why in health reform we  
94 bolster the very important work that the U.S. Preventative  
95 Services Taskforce does by providing increased funding so  
96 that they can analyze more studies and make more prevention

97 recommendations. The evidence-based recommendations that  
98 receive the highest ratings from the taskforce such as  
99 mammography screenings will be covered by all insurance  
100 carriers participating in the health insurance exchange and  
101 by Medicaid, and while Medicare already covers these services  
102 under health reform, beneficiaries would no longer face cost-  
103 sharing requirements to receive them.

104 In addition in health reform, we must also improve the  
105 quality of care that is provided in this country as Ms.  
106 Castor is seeking to do with her bill. Tens of thousands of  
107 Americans die to preventable medical errors every year.  
108 Billions of dollars are wasted on low-quality care. We as a  
109 Nation must do better. Improving quality is a concept we  
110 picked up in health reform as well. We require the Secretary  
111 to establish national priorities for quality improvement and  
112 we also create a center for quality improvement. This center  
113 will develop and encourage the use of best practices for  
114 quality assurance and will provide implementation grants to  
115 those who are already doing innovative work to improve the  
116 quality of care. Using breast cancer as an example, we can  
117 and must do better to ensure that all Americans receive the  
118 highest quality care and that we collect data that will help  
119 us continuously improve as more information becomes known  
120 about the medical system and specific diseases.

121 I want to thank all of our witnesses. I know we are  
122 going to start after opening statements with the Members'  
123 panel. I would say I guess it is clear from my opening  
124 statement that in many cases some of the things in these  
125 bills hopefully will be addressed in the larger health care  
126 reform bill but I don't mean to suggest that that takes away  
127 from the need for us to have this hearing today or to move  
128 forward with these bills. It may very well be that some  
129 things are included and some are not, and so this is a  
130 legislative hearing and the intention would be to move these  
131 bills, but we also have to see what is included in the health  
132 care reform as well.

133 [The prepared statement of Mr. Pallone follows:]

134 \*\*\*\*\* COMMITTEE INSERT \*\*\*\*\*

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135           Mr. {Pallone.} So thank you, and with that I would  
136 yield to our ranking member, Mr. Deal.

137           Mr. {Deal.} Thank you, Chairman Pallone. Thank you for  
138 holding the hearing and thanks to our colleagues for  
139 appearing before us today and all the other distinguished  
140 witnesses whose testimony we will certainly look forward to  
141 hearing.

142           All of us, I think, understand the importance of the  
143 topic that is before us today. Many of us have cosponsored  
144 many of the legislative agenda items that are before the  
145 Committee. I for one have cosponsored H.R. 1740 because I  
146 think it is important for early diagnosis and treatment of  
147 breast cancer as well as the continued effort to educate  
148 young women about this particular disease. Now, we have  
149 dealt with a variety of issues over the years and most  
150 recently highlighted by testimony from Ranking Member Barton  
151 about a constituent who in the midst of dealing with breast  
152 cancer had her policy canceled. The House has dealt with  
153 that when we passed H.R. 758 by an overwhelming vote of 421  
154 to 2, so we have begun the process, I think, of dealing with  
155 many of the issues surrounding the treatment and diagnosis of  
156 breast cancer.

157           But as we continue to deal with how we can best combat

158 this disease, I believe that as stewards of the taxpayers'  
159 dollars that we must make sure that these dollars are being  
160 most in the most appropriate way, particularly those that are  
161 with the NIH and CDC. We must assure that these limited  
162 resources are appropriately expended to fight all diseases  
163 including breast cancer, and I have particular concerns about  
164 some of the expenditures in both NIH and CDC that would  
165 appear to be far beyond the normal pale of what people regard  
166 as important research for those two agencies to be  
167 supervising.

168       So I look forward to the testimony and I welcome our  
169 colleagues on the first panel. I yield back.

170       [The prepared statement of Mr. Deal follows:]

171 \*\*\*\*\* COMMITTEE INSERT \*\*\*\*\*

|  
172 Mr. {Pallone.} Thank you, Mr. Deal.

173 Let me mention to everybody, that is just a recess. We  
174 are not voting, just so you know.

175 I recognize the gentlewoman from Colorado, Ms. DeGette.

176 Ms. {DeGette.} Thank very much, Mr. Chairman, and out  
177 of respect for our intrepid and courageous witnesses in our  
178 first panel, I will waive my opening statement and submit my  
179 very excellent statement that everyone will be able to read  
180 in the record. Thank you.

181 [The prepared statement of Ms. DeGette follows:]

182 \*\*\*\*\* COMMITTEE INSERT \*\*\*\*\*

|  
183 Mr. {Pallone.} Thank you.

184 Next is the gentleman from Missouri, Mr. Blunt.

185 Mr. {Blunt.} Thank you, Mr. Chairman. I do have a  
186 statement. I will submit it for the record as well. I am  
187 pleased we are having this hearing. I am pleased to be a  
188 cosponsor of H.R. 1740, the EARLY Act, with my good friend,  
189 Ms. Wasserman Schultz, and look forward to the hearing.

190 [The prepared statement of Mr. Blunt follows:]

191 \*\*\*\*\* COMMITTEE INSERT \*\*\*\*\*

|  
192 Mr. {Pallone.} Thank you.

193 The gentlewoman from California, Ms. Harman.

194 Ms. {Harman.} Thank you, Mr. Chairman. I will be brief  
195 but I want to salute our colleagues but especially our  
196 colleague, Debbie Wasserman Schultz, for her courage, her  
197 passion and her example. Many of us wore pink today in  
198 solidarity with her. We are strong supporters of her bill.  
199 Hopefully we will find a way now that it is in acceptable  
200 form to Committee staff to include it in the health care bill  
201 with the robust public option that we are going to pass on  
202 the House Floor one of these days.

203 Just briefly, I have a brother who is an oncologist. I  
204 couldn't have been prouder when he was given the Healer of  
205 the Year award by Marin County, California, for his work on  
206 breast cancer. Breast cancer attacks oldies, grandmas like  
207 me, but it also attacks beautiful young women like Debbie  
208 Wasserman Schultz and hopefully not my daughters, who are a  
209 bit younger than she is, and hopefully not my granddaughter,  
210 who is a lot younger than she is. So this is something we  
211 all have experience with. All of us know people who have  
212 breast cancer. Hopefully they all will be survivors and most  
213 of us are very responsive to the Susan G. Komen and other  
214 efforts to raise awareness.

215 I just want to say that these bills are all good. I am  
216 rousingly enthusiastic about Debbie Wasserman Schultz's bill  
217 and in that context I would like to ask unanimous consent to  
218 insert in the record a statement by the United Jewish  
219 Communities in support of that bill.

220 [The information follows:]

221 \*\*\*\*\* COMMITTEE INSERT \*\*\*\*\*

|  
222           Mr. {Pallone.} Without objection, so ordered. I guess  
223 I didn't get the memo to wear the pink. I see Jerry did.  
224 But I was given a pink bat in lieu of a gavel today, so maybe  
225 we will use that.

226           Ms. {Harman.} Well, Jerry Nadler represents two of my  
227 kids on the west side of New York, one of whom is female, so  
228 it is a good thing that he has high awareness of this. I  
229 just want to add a couple of facts. One, advances in cancer  
230 research and treatments have greatly improved survival rates.  
231 In the 1960s, a woman diagnosed with breast cancer had only a  
232 63 percent chance of living longer than 5 years. Now it is  
233 89 percent. Hispanic and African-American women have a lower  
234 survival rate than the rest of the population, so clearly we  
235 have a lot of work to do on reducing racial disparities.

236           And finally, next Friday, October 16, is National  
237 Mammography Day. It is a day when radiologists provide free  
238 or discounted screening mammograms, and hopefully the women  
239 in my district and all those can hear us at this hearing will  
240 take advantage of this. Breast cancer is a terrible opponent  
241 but it is a beatable one. I yield back, Mr. Chairman.

242           [The prepared statement of Ms. Harman follows:]

243 \*\*\*\*\* COMMITTEE INSERT \*\*\*\*\*

|  
244 Mr. {Pallone.} Thank you.

245 Next is the gentleman from Georgia, Mr. Gingrey.

246 Mr. {Gingrey.} Mr. Chairman, thank you. I did have an  
247 opening statement I would like to give.

248 Deaths from breast cancer among women have dropped more  
249 than 2 percent each year since 1990 due in large part to the  
250 intervention of improved treatments and early detection of  
251 the disease. A study published in 2008 found the United  
252 States has the highest rate of survival for breast and  
253 prostate cancers in the world. These statistics are just a  
254 small example of the quality that makes our health care  
255 system a leader throughout the world. Unfortunately, being  
256 the best is not the entire story. While our health care  
257 system is a benefit to many with breast cancer, the disease  
258 is still the second most common cancer that women are forced  
259 to deal with in the United States. It is estimated that  
260 192,000 new cases of invasive breast cancer are expected to  
261 be diagnosed this year and roughly 40,000 women are expected  
262 to die from the disease in 2009, 40,000. These are sobering  
263 statistics that beg our thoughtful consideration.

264 Therefore, I would like to commend the efforts of our  
265 panelists and all those who strive each and every year to  
266 bring attention and awareness to a disease that has impacted

267 many of our friends and colleagues, some of whom are sitting  
268 here with us today as we well know. I applaud their efforts  
269 to raise the awareness and early detection of breast cancer  
270 among our Nation's patients, and I look forward to hearing  
271 their testimony today.

272         However, we must also take a step back and look at the  
273 legislation before us in the context of the overall reform  
274 plan reported from this Committee at the end of July. From  
275 what I surmise, two of the bills before us today address  
276 federal requirements on insurance plans that would in essence  
277 I think, become moot because of H.R. 3200. If H.R. 3200 were  
278 to become law, this Congress would not be deciding what  
279 benefits insurance companies must contain or what measures  
280 should be used to ensure non-citizens cannot use taxpayer  
281 dollars to purchase health insurance. Those would be the  
282 purview of a political appointee with little regard for the  
283 will of the people.

284         After the outpouring of concern and constructive  
285 criticism for the President's plan during the August recess,  
286 I had hoped to come back to these hallowed walls and found a  
287 new Congress open and willing to work in a bipartisan fashion  
288 for the benefit of our constituents. Today as we sit here  
289 with the specter of H.R. 3200 hanging over our heads, it is  
290 looking more and more that that hope to be a false one. Mr.

291 Chairman, it seems the lessons of August have not been  
292 learned by some of my colleagues on the other side of the  
293 aisle. I yield back my time.

294 [The prepared statement of Mr. Gingrey follows:]

295 \*\*\*\*\* COMMITTEE INSERT \*\*\*\*\*

|  
296 Mr. {Pallone.} Thank you, Mr. Gingrey.

297 Next is our chairman, Mr. Dingell.

298 Mr. {Dingell.} Mr. Chairman, I thank you. Good  
299 morning.

300 I would first like to thank you for holding this  
301 hearing. It is an important one and it is an opportunity to  
302 learn more about the four breast cancer bills before us  
303 today. Breast cancer is the second most common type of  
304 cancer amongst women in the United States so it is important  
305 for us to continue a vigorous examination of how to best  
306 prevent and treat this disease. In 2009, an estimated  
307 192,370 new cases of invasive breast cancer will be diagnosed  
308 among women, and approximately 40,107 of these women are  
309 expected to die from the disease. An additional 1,920 cases  
310 of breast cancer are expected to occur amongst men. In my  
311 home State of Michigan alone, there will be an estimated  
312 6,480 new cases this year and 1,350 deaths. It is estimated  
313 that about \$8.1 billion is spent in this Nation every year  
314 for the treatment of breast cancer. While real strides are  
315 being made against the disease, the 5-year survival rate is  
316 98 percent when detected early but too many women continue to  
317 lose the battle against breast cancer for want of proper  
318 treatment and proper early diagnosis.

319 H.R. 995 would require a group health plan that provides  
320 diagnostic mammography for women over 40 to also cover an  
321 annual screening mammography and an MRI for high-risk women.  
322 The National Cancer Institute has recommended that women 40  
323 and over should have a mammogram once every 1 or 2 years.  
324 Doctors and patients should make the decision whether to have  
325 a mammogram based on risk factors, not the cost.

326 Another bill under consideration is H.R. 1691, the  
327 Breast Cancer Patient Protection Act, of which I am a  
328 sponsor. H.R. 1691 would ensure that women undergoing  
329 mastectomies would be guaranteed 48 hours of hospital care  
330 unless the provider and the patient determine a shorter stay  
331 is appropriate. This is again aimed at dealing with the  
332 problem of drive-through mastectomies and other things of  
333 that character as provided by the health insurance providers  
334 of this country. The legislation would also protect  
335 physicians who provide quality care for breast cancer  
336 patients from retaliation by health maintenance organizations  
337 and other insurance companies seeking to maximize profits at  
338 the expense of patient care. This bill is of great  
339 importance to me because a member of my staff in Michigan was  
340 a victim of these unscrupulous insurance company practices  
341 when she was sent home after a mastectomy in considerable  
342 pain with no support to manage her condition. She ultimately

343 succumbed to her cancer but the heartless way in which her  
344 insurance company treated her was an outrage. Guaranteeing  
345 that treatment decisions are made by the provider in  
346 consultation with the patient, taking into account the  
347 patient's unique medical needs, is the cornerstone of good,  
348 successful and, believe it or not, inexpensive or the least  
349 expensive medical care.

350 H.R. 1740 would direct the CDC to develop and implement  
351 a national education campaign about the threat that breast  
352 cancer poses to young women of all ethnic and cultural  
353 backgrounds and the particular heightened risks of certain  
354 groups of our women. It is important that we examine the  
355 ways to educate our young women and medical professionals  
356 about breast cancer in young women.

357 The final bill considered today, H.R. 2279, would  
358 address the disparities in breast cancer diagnosis and  
359 treatment by requiring providers to report their practices to  
360 encourage doctors to offer adequate care to all irrespective  
361 of race, income, age or health insurance status.

362 Together these bills will protect women from drive-  
363 through mastectomies as well as advanced breast cancer  
364 protection and treatment amongst high-risk communities, young  
365 populations and minorities. This hearing coincides with  
366 National Breast Cancer Awareness Month and will shine light

367 on issues of great importance to women and their families. I  
368 look forward to the testimony of today's witnesses and I  
369 commend you for the hearing, and I thank you, Mr. Chairman.

370 [The prepared statement of Mr. Dingell follows:]

371 \*\*\*\*\* COMMITTEE INSERT \*\*\*\*\*

|  
372 Mr. {Pallone.} Thank you, Chairman Dingell.

373 Next is one of the sponsors of the bill--oh, I am sorry.

374 Next is the gentleman from Texas, Mr. Burgess.

375 Mr. {Burgess.} Mr. Chairman, in the interest of time,  
376 and I know we have got votes, I will submit my statement for  
377 the record.

378 [The prepared statement of Mr. Burgess follows:]

379 \*\*\*\*\* COMMITTEE INSERT \*\*\*\*\*

|  
380 Mr. {Pallone.} Thank you, Dr. Burgess.

381 Next is one of our prime sponsors of the legislation,  
382 the gentlewoman from Florida, Ms. Castor.

383 Ms. {Castor.} Chairman Pallone, thank you very much for  
384 convening this timely hearing on breast cancer legislation  
385 during National Breast Cancer Awareness Month.

386 Breast cancer is still a brutal killer in America but we  
387 are going to continue to fight and we are going to make  
388 progress, and we are going to make progress due in large part  
389 to the leaders who are here today, to my colleagues here on  
390 the Health Subcommittee but to these brave Members of  
391 Congress that represent hundreds of thousands of people and  
392 many, many women who have struggled with breast cancer.

393 Congresswoman Rosa DeLauro, Congressman Jerry Nadler and my  
394 good friend from Florida, Congresswoman Debbie Wasserman  
395 Schultz. Congresswoman Wasserman Schultz has been a fine  
396 example of perseverance and a great role model for anyone  
397 that has been diagnosed with breast cancer, and I am proud to  
398 be a cosponsor of her bill.

399 I am also eager to hear from the top experts in the  
400 field today on our latest legislation, and Mr. Chairman, our  
401 colleague, Congresswoman Dr. Donna Christensen, is my partner  
402 on my bill, H.R. 2279, the Eliminating Disparities in Breast

403 Cancer Treatment Act, that we will consider today. I would  
404 like to thank her for all of her attention to disparate  
405 diagnosis and treatment that still plagues health care in  
406 America.

407         It is not secret that quality health care in the United  
408 States is not equally accessible to all of our communities.  
409 As a Committee, we have worked diligently for the better part  
410 of this year to improve health care in America and to make  
411 quality care affordable and accessible for all, and we are  
412 closer to that than ever before but we still have these  
413 underlying issues of disparate diagnosis and treatment that  
414 must be addressed directly, and one of the most disturbing  
415 involves breast cancer in women of color. Overall breast  
416 cancer survival rates in the last two decades have improved  
417 with one exception: minority women. Women of color suffer  
418 from significantly higher death rates after diagnosis than  
419 white women. The American Cancer Society reports that delays  
420 in receiving care after breast cancer diagnosis are greater  
421 for African-American women than for white women. African-  
422 American women with breast cancer are less likely to receive  
423 standard therapy than white women. African-American and  
424 Hispanic patients are significantly more likely than white  
425 patients to be diagnosed at a more advanced stage of breast  
426 cancer. And regardless of insurance status, African-American

427 women are almost two times more likely to be diagnosed with  
428 an advanced stage of breast cancer than white women and  
429 Hispanic women are about one and a half times more likely to  
430 be diagnosed with an advanced stage of breast cancer than  
431 white women. African-American women are 10 percent more  
432 likely not to receive tests to determine if breast cancer has  
433 spread to axillary underarm lymph nodes. This screening is  
434 essential to preventing the spread of cancer to other parts  
435 of the body. Health insurance status, race, income and  
436 educational background are directly linked to irregularity in  
437 administering this vital screening. Substantial disparities  
438 remain regarding cancer diagnosis and treatment.

439       So in order to eliminate this unacceptable variance in  
440 treatment and quality care, it is necessary that we create  
441 real incentives and requirements for medical professionals to  
442 provide the best care. All patients should receive the most  
443 modern and high-standard treatment for their conditions. So  
444 our bill seeks to put an end to the inequities in treatment  
445 for breast cancer and will help ensure that every patient has  
446 access to the most appropriate care. The legislation will  
447 implement breast cancer treatment performance measures,  
448 requiring the Secretary of HHS to work with a national  
449 quality forum to develop standard best practices for breast  
450 cancer treatment. These measures will address patient

451 outcomes, the process for delivering medical care related to  
452 breast cancer treatment, patient counseling and engagement in  
453 decision-making, overall patient experience, physician care  
454 coordination and then the Secretary will develop a 6-year  
455 breast cancer treatment quality performance initiative. In  
456 years 1 through 3, physicians will be encouraged to follow  
457 the new recommendations and report their practices on a  
458 voluntary basis. In years 3 through 6 reporting will be  
459 required and the Secretary will evaluate the care that is  
460 furnished to patients. Low-quality treatment from providers  
461 will result in reduced Medicare payments for those  
462 physicians. Improvements in treatment will be recognized and  
463 payments will be scaled based on the care provided. The  
464 Secretary will be required to report to Congress so we can  
465 keep track of the progress.

466         Mr. Chairman, this legislation will help eliminate  
467 disparities in the treatment of breast cancer. We must  
468 continue to use all of our expertise and modern tools to  
469 fight this brutal killer, improve diagnosis and improve  
470 treatment. It will save lives, it will save money and it  
471 will save heartache.

472         Thank you very much. I look forward to hearing from the  
473 panels.

474         [The prepared statement of Ms. Castor follows:]

475 \*\*\*\*\* COMMITTEE INSERT \*\*\*\*\*

|  
476 Mr. {Pallone.} Thank you.

477 The gentleman from Illinois, Mr. Shimkus.

478 Mr. {Shimkus.} Thank you, Mr. Chairman. I want to  
479 welcome my colleagues here. They are all sincere and  
480 respected public policy experts, and I appreciate their  
481 attendance, and I yield back my time.

482 [The prepared statement of Mr. Shimkus follows:]

483 \*\*\*\*\* COMMITTEE INSERT \*\*\*\*\*

|  
484 Mr. {Pallone.} Thank you.

485 The gentlewoman from Illinois, Ms. Schakowsky.

486 Ms. {Schakowsky.} Thank you, Mr. Chairman. I will put  
487 my full statement in the record, but I do want to thank all  
488 of my colleagues, Debbie Wasserman Schultz and Rosa DeLauro  
489 and Jerry Nadler and Kathy Castor for the wonderful bills  
490 that I am proud to be a cosponsor of.

491 I just do want to tell you that Chicago has one of the  
492 largest disparities in death rates as a result of breast  
493 cancer. A report released in 2007 showed that breast cancer  
494 kills minority women at a rate of 68 percent higher than  
495 white women, mostly because of inequities and access to  
496 quality and affordable care. And I want to give a shout-out  
497 to an organization. We are actually going to have a briefing  
498 with them next week. Pin-A-Sister is a Chicago-based  
499 organization started by Access Community Health Center.  
500 Every Mothers Day the organization coordinates an event in  
501 black and Latino churches. The women in the congregation are  
502 invited to place a pin on a sister to empower her to learn  
503 more about breast cancer and to show she is not alone in her  
504 experience with breast cancer. But they need help.

505 These bills that you have sponsored and that I feel  
506 certain that will pass are really going to help them and all

507 women, those facing breast cancer and potentially those who  
508 may face it in the future. Thank you very much. I yield  
509 back.

510 [The prepared statement of Ms. Schakowsky follows:]

511 \*\*\*\*\* COMMITTEE INSERT \*\*\*\*\*

|  
512 Mr. {Pallone.} Thank you.

513 The gentlewoman from Tennessee, Ms. Blackburn.

514 Mrs. {Blackburn.} Thank you, Mr. Chairman, and I thank  
515 our colleagues for the good work that they have done and the  
516 attention that they have brought to this issue and we are  
517 delighted that you are here. I will place my full statement  
518 in the record.

519 I do want to highlight some of our volunteers in  
520 Tennessee that have done exceptional work on the issue of  
521 breast cancer. Our Tennessee Breast Cancer Coalition really  
522 has taken the lead in Tennessee. We do know that the work we  
523 did last year on the Breast Cancer Environmental Research  
524 Center Act was very important. This is something the  
525 environmental pressures that come to bear on Tennessee women  
526 is something that has gained a lot of attention in our State  
527 and has caused a lot of concern, and we have several  
528 facilities that are doing a great deal of wonderful research-  
529 -the UT Cancer Institute, the Vanderbilt Ingram Cancer Center  
530 and the Minnie Pearl, Sarah Cannon Center and so I highlight  
531 the good work that is being done there.

532 In Tennessee, we have 3,970 new cases of breast cancer  
533 that will be diagnosed this year, and 910 women will probably  
534 end up losing their life to this disease. We note the

535 legislation before us will help assist the good ongoing  
536 research equally in the manner that the legislation we passed  
537 last year did and we look forward to eradicating the disease  
538 and certainly making a difference in the lives of men and  
539 women that are affected by this, and I thank you for the  
540 hearing and yield my time.

541 [The prepared statement of Mrs. Blackburn follows:]

542 \*\*\*\*\* COMMITTEE INSERT \*\*\*\*\*

|  
543 Mr. {Pallone.} Thank you.

544 The gentleman from Utah, Mr. Matheson.

545 Mr. {Matheson.} Thanks, Mr. Chairman. I will submit my  
546 full written statement for the record, but just very briefly,  
547 I would point out that it is appropriate we have four  
548 different bills today. This is a complicated issue and there  
549 are a lot of aspects in terms of addressing and trying to  
550 fight this disease that we should consider as a Committee,  
551 and I want to thank the lead sponsors, Representative Castor,  
552 Representative Nadler, Representative DeLauro and  
553 Representative Wasserman Schultz for championing this issue.  
554 Congresswoman DeLauro has been such a great advocate and I  
555 was an original cosponsor. I remember we passed this in the  
556 House last time and hopefully we get it across the finish  
557 line this time.

558 You know, a lot of people point out different  
559 populations that are affected differently, and I would just  
560 highlight one interesting demographic in my home State where  
561 in Utah the incidence of breast cancer is actually much lower  
562 than the national average and yet the mortality rate is about  
563 the same, and that is because we have a problem where it is  
564 usually diagnosed at later stages. That is why Congresswoman  
565 Wasserman Schultz's bill is of particular interest to me that

566 will help in my State. And it just points out that you hear  
567 these opening statements from people around the country with  
568 different constituencies and whatnot and there are so many  
569 ways we need to try to attack this issue.

570 I commend the Committee for holding this hearing and  
571 bringing all these folks together. I look forward to  
572 advocating for all these bills. Mr. Chairman, I want to once  
573 again thank my colleagues for being here and I will yield  
574 back my time.

575 [The prepared statement of Mr. Matheson follows:]

576 \*\*\*\*\* COMMITTEE INSERT \*\*\*\*\*

|  
577 Mr. {Pallone.} Thank you.

578 The gentlewoman from the Virgin Islands, Ms.  
579 Christensen.

580 Mrs. {Christensen.} Thank you, Mr. Chairman, and I  
581 thank you and the ranking member for holding this hearing on  
582 such an important issue and making, we hope, this Breast  
583 Cancer Awareness Month a decisive one in the fight against  
584 breast cancer. I would like to welcome my colleagues as  
585 well.

586 With these bills, we not only expand access to  
587 mammography and other often lifesaving screening technologies  
588 but we protect and ensure the health care coverage for breast  
589 cancer patients, educate women earlier about breast cancer  
590 and eliminate the breast cancer disparities that have a  
591 disastrous impact on far too women of color. I would like to  
592 thank Representatives Nadler, DeLauro, Castor, with whom I  
593 worked on 2279, and especially Congresswoman Debbie Wasserman  
594 Schultz, herself a breast cancer survivor, especially for  
595 your bill's emphasis on educating younger women earlier about  
596 breast cancer.

597 It is unacceptable that today one in every eight women  
598 will have invasive breast cancer at some point in her life  
599 and that breast cancer remains the second leading cause of

600 cancer death for women in this country, but as grim as these  
601 statistics are, they are even worse when you consider racial  
602 and ethnic disparities in breast cancer incidence and  
603 mortality and prevention. For example, while African-  
604 Americans have lower breast cancer incidence rates than their  
605 white counterparts, they are more likely to die from the  
606 disease. Latina, American Indian and Asian-American women  
607 are not only disproportionately more than likely than their  
608 white counterparts to not have a mammogram in the recent 2  
609 years, but finally, while breast cancer death rates have been  
610 on the decline since 1990 overall, we find that that the 5-  
611 year breast cancer survival rate for American Indian women is  
612 lower than any other population group of women.

613         So these statistics suggest that while we have made  
614 great progress in the fight against breast cancer much to the  
615 credit of the witnesses we will hear from today and  
616 continuing with the legislation before us. We have a long  
617 way to go and I look forward to today's testimonies and  
618 discussions and anticipate that this hearing will serve as  
619 the impetus needed to take our collective fight against  
620 breast cancer and every cancer really to the very next level,  
621 and I thank you. I yield back.

622         [The prepared statement of Mrs. Christensen follows:]

623 \*\*\*\*\* COMMITTEE INSERT \*\*\*\*\*

|  
624 Mr. {Pallone.} Thank you.

625 The gentleman from Maryland, Mr. Sarbanes.

626 Mr. {Sarbanes.} Thank you, Mr. Chairman. I will be  
627 very brief.

628 These are all incredibly important measures, and I just  
629 want to salute our colleagues and my colleague, Kathy Castor,  
630 for their work on this. I am embarrassed, Debbie, that I am  
631 not wearing any pink today, but I am turning pink with  
632 embarrassment at that, so that will have to do.

633 Anyway, congratulations on your work. We look forward  
634 to your testimony.

635 [The prepared statement of Mr. Sarbanes follows:]

636 \*\*\*\*\* COMMITTEE INSERT \*\*\*\*\*

|  
637 Mr. {Pallone.} Thank you.

638 The gentleman from Georgia, Mr. Barrow. I will mention  
639 to members that we have three votes, a 15--I am sorry, four  
640 votes. There is a 15 and then three 5s. Mr. Barrow, if you  
641 would like to make an opening, go ahead.

642 Mr. {Barrow.} Thank you, Mr. Chairman. I would.

643 It is estimated that one in eight women will develop  
644 breast cancer over their time and it is the leading cause of  
645 death among women age 45 and older. This disease is far too  
646 preventable and too treatable for these numbers to be so  
647 high. I know because my mother, who turns 89 years of age  
648 today, is a 35-year survivor of breast cancer. Curing breast  
649 cancer is a huge challenge and it can only happen with good  
650 science, adequate funding, effective treatments and greater  
651 awareness and education.

652 These bills we are addressing here today represent small  
653 but important steps along the way. October is National  
654 Breast Cancer Awareness Month. This gives us an excuse to  
655 come here today and work on this legislation but I look  
656 forward to the day when this month will not be a time to  
657 raise awareness but a time to celebrate how our collective  
658 efforts actually led to the eradication of breast cancer. I  
659 want to thank Chairman Pallone and Ranking Member Deal for

660 addressing this important issue in our Subcommittee as well  
661 as Representatives Nadler, DeLauro and especially my  
662 colleagues, Congresswoman Wasserman Schultz and Congresswoman  
663 Castor, for introducing these critical bills that promote  
664 breast cancer prevention, research, treatment and quality of  
665 care. Thank you, and I yield back.

666 [The prepared statement of Mr. Barrow follows:]

667 \*\*\*\*\* COMMITTEE INSERT \*\*\*\*\*

|  
668           Mr. {Pallone.} Thank you. I think that concludes our  
669 opening. Now, we could get a couple of you in. I don't  
670 think we can get all three of you. I will dispense with my  
671 remarks other than to say the three of you are wonderful, and  
672 two of you are cancer survivors. All three of you have been  
673 champions of this and other issues so effectively. If  
674 anybody can get anything done, it is the three of you, and I  
675 start with Congressman Nadler.

|  
676 ^STATEMENTS OF THE HONORABLE JERROLD NADLER, MEMBER OF  
677 CONGRESS; THE HONORABLE ROSA L. DELAURO, MEMBER OF CONGRESS;  
678 AND THE HONORABLE DEBBIE WASSERMAN SCHULTZ, MEMBER OF  
679 CONGRESS

|  
680 ^STATEMENT OF JERROLD NADLER

681 } Mr. {Nadler.} Thank you, Chairman Pallone, Ranking  
682 Member Deal and the members of the Subcommittee. Thank you  
683 for convening this hearing and for inviting me to testify  
684 today about H.R. 995, the Mammogram and MRI Availability Act.

685 I also want to thank the breast cancer advocacy groups  
686 for coming to testify about the work they do, the problems we  
687 face in the fight against breast cancer and the ways in which  
688 they and their organizations are helping to educate, screen,  
689 treat and care for women living with and at risk of  
690 developing breast cancer.

691 We all know people near and dear to us who have battled  
692 breast cancer, my wife among them for the last 3 years. We  
693 all know the statistics. Breast cancer is the second leading  
694 cause of death of women in the United States, the leading  
695 cause of death of women age 40 to 49. This year alone, more  
696 than 40,000 women in the United States will die from breast

697 cancer. More than 192,000 new cases will be discovered.

698 We also know that in addition to the need to find a  
699 cure, prevention is the difference between life and death.  
700 In 2005, the National Institute of Cancer Study confirmed  
701 that mammograms contributed to a pronounced drop in the  
702 number of breast cancer deaths. Study after study has found  
703 that yearly mammograms, annual mammograms done from age 40 on  
704 help find tumors at their smallest and most treatable stage.  
705 That is why the American Cancer Society and others recommend  
706 that women age 40 and older should have yearly mammograms,  
707 and that is why I introduced H.R. 995, a bipartisan,  
708 commonsense bill to ensure coverage of annual mammograms for  
709 this population of women.

710 While many insurance plans cover diagnostic mammograms,  
711 that is, mammograms used to diagnose whether an already known  
712 mass or tumor is cancerous, many insurance plans do not cover  
713 screening mammograms for the purpose of detecting tumors in  
714 the first place. Based on the research and what we know  
715 about breast cancer, this is simply unacceptable, and women  
716 and their families deserve better. We would save many, many  
717 lives if all plans covered annual screening mammograms for  
718 women of age 40 and above.

719 As we have learned, mammograms on their own do not  
720 detect every malignant tumor. For women at particularly high

721 risk of breast cancer, women who have a strong family history  
722 of breast cancer where a woman's mother, grandmother, sister  
723 or daughter was diagnosed with breast cancer or those women  
724 with a BRCA1 or 2 genes who have a genetic predisposition to  
725 developing the disease, MRIs help detect more tumors at their  
726 earliest, most treatable stages that mammograms cannot  
727 detect. For this population of women who are particularly  
728 susceptible and at high risk of developing breast cancer, the  
729 American Cancer Society recommends an annual mammogram and an  
730 annual MRI. As with coverage for mammograms, insurance  
731 companies do not routinely cover screening MRIs, even for  
732 this high-risk population of women.

733 H.R. 995 would make these important screening exams  
734 available to the women who need them most. So, in other  
735 words, what this bill would do is to say that any health  
736 insurance plan that provides coverage for diagnostic  
737 mammograms must provide coverage for screening mammograms for  
738 women annually over 40 and for the high-risk population of  
739 women over 40 for MRIs annually as well. While women should  
740 consult a doctor before undergoing a mammography or MRI,  
741 nothing in this bill requires a woman to seek a doctor's  
742 referral prior to receiving one of these lifesaving screening  
743 exams nor does the bill require women to undergo any tests  
744 unless she chooses to do so.

745           As the Subcommittee well knows, Congress is on course to  
746 pass historic health care reform bill this year. That  
747 legislation contains important provisions that would  
748 eliminate copays and deductibles for recommended prevention  
749 services. These recommendations should include screening  
750 mammograms. However, neither House of Congress has passed  
751 the legislation. Furthermore, even if passed, delays upward  
752 of 5 years or more could continue to limit women's access to  
753 these exams. Therefore, passage of major health reform won't  
754 necessarily prevent these women from continuing to fall  
755 through the cracks. Additionally, the prevention measures  
756 likely to be included in the final health care reform package  
757 do not currently include coverage for MRIs for high-risk  
758 women. Thus, the women most at risk, the women with a strong  
759 family history of the presence of breast cancer as well as  
760 those who are genetically predisposed to the disease will  
761 continue to be left without access to these lifesaving exams.  
762 Only passage of H.R. 995 either as a standalone bill or by  
763 inclusion of its provisions in the comprehensive bill that  
764 this Committee is helping to shape now will ensure that these  
765 women have the coverage they need on which their lives may  
766 very well depend.

767           Mr. Chairman, with the passage of this bill or with its  
768 inclusion in the overall bill when that passes, women age 40

769 and older as well as those women at particularly high risk of  
770 developing breast cancer will no longer continue to fall  
771 through the cracks. With this legislation, these women will  
772 be guaranteed coverage for life-saving screening exams. As  
773 we wait to find a cure, ensuring coverage for screening  
774 mammograms for all women age 40 or older and where indicated  
775 for the high-risk population of women over 40 for MRIs as  
776 well could mean tremendous benefits for many, many women and  
777 their families in the fight against breast cancer.

778         Mr. Chairman, I thank you again for giving me an  
779 opportunity to discuss this bill, H.R. 995, the Mammogram and  
780 MRI Availability Act, and for holding this important hearing  
781 on women's health. I look forward to working with you as  
782 well as my colleagues on the Subcommittee to pass this  
783 legislation in one or the other form. Thank you very much.

784         [The prepared statement of Mr. Nadler follows:]

785 \*\*\*\*\* INSERT 1 \*\*\*\*\*

|

786 Mr. {Pallone.} Thank you.

787 Congresswoman DeLauro.

|  
788 ^STATEMENT OF ROSA L. DELAURO

789 } Ms. {DeLauro.} Thank you very much, Mr. Chairman, and  
790 thank you, Ranking Member Deal, for hosting this effort  
791 today. I also want to say thank you to this Subcommittee and  
792 to the full Committee on a bipartisan basis that have  
793 supported the Breast Cancer Patient Protection Act, and I  
794 appreciate that as the women around the country do. Also, my  
795 colleagues, Jerry Nadler, Debbie Wasserman Schultz, all of  
796 whom have--Kathy Castor, Donna Christensen, try to come to  
797 grips with what is a singularly big health issue for women  
798 around the country, and I would just say to Debbie that her  
799 courage and her tenacity in this effort is well known, and  
800 she clearly is a voice for young women. To all of the  
801 advocates who are here today, thank you. We can't do this  
802 without you. It is an honor to work with you and your  
803 efforts again also keep us strong and determined to make sure  
804 we pass good legislation.

805 It was 13 years ago that Dr. Kristin Zarfos, who is a  
806 Connecticut breast surgeon, told me that HMOs were forcing  
807 her to discharge her patients before they were ready,  
808 sometimes just hours after a mastectomy. She testified  
809 before this Subcommittee last year that insurers suddenly

810 refused to pay for reasonable hospital stay regardless of any  
811 underlying or complex medical problems that patients might  
812 have--diabetes, heart disease. This is still happening.  
813 Patients continue to be discharged with no consideration for  
814 adverse reactions to anesthesia, postoperative pain or even  
815 when they are awake enough to understand their discharge  
816 instructions. At the Subcommittee hearing last year that was  
817 convened, we had a breast cancer patient, Alva Williams. She  
818 testified she had a mastectomy on March 6, 2006, was sent  
819 home several hours after surgery. The insurance company  
820 would not cover an overnight stay. The family didn't receive  
821 proper training on how to care for her. She developed an  
822 infection in the incisions and recovering from that infection  
823 caused Ms. Williams' chemotherapy treatments to be delayed 6  
824 weeks. Arizona--a woman's story on Lifetime TV website: ``I  
825 had a double bilateral mastectomy in June of this year. I was  
826 discharged within 2 hours after surgery. I had severe  
827 complications that later resulted in being readmitted to the  
828 hospital within the first week post surgery.'' The stories  
829 go on, and my testimony has been submitted. There is a woman  
830 in Kansas City whose husband was a physician and she found  
831 that it was difficult even with a caregiver who was a  
832 physician.

833           So this is happening across the Nation, which is why in

834 my view we need to pass the Breast Cancer Patient Protection  
835 Act. It says that simply, very simply, adequate recovery  
836 time in the hospital should not be negotiable. The last  
837 thing that any woman should be doing at this time is fighting  
838 with their insurance company. The bill does not mandate, it  
839 does not mandate a 48-hour hospital stay. If a patient  
840 chooses to go home sooner, fine. Nor does it set 48 hours as  
841 a maximum amount of time a woman can stay in the hospital.  
842 It says that any decision in favor of shorter, longer  
843 hospital stay would be made by a patient and her doctor and  
844 not by an insurance company.

845 I have been in the hospital many months, and let me just  
846 tell you, it is not for everyone. It is not where you want  
847 to spend your time. But it is important to know that  
848 successful outpatient mastectomy programs have been extremely  
849 careful to empower their patients through education,  
850 monitoring outcomes and working intensely to minimize  
851 complications.

852 Last year, 421 Members of Congress voted to enact this  
853 legislation, bipartisan support. We introduced it this year,  
854 my colleague, your colleague, Joe Barton. Mr. Dingell has  
855 spoken out on it. Lifetime Television has a petition calling  
856 for the Breast Cancer Patient Protection Act's passage.  
857 Nearly 24 million people have signed on to this petition. We

858 have 236 cosponsors. Senator Snowe, Senator Landrieu, 17  
859 cosponsors in the Senate. We are ready to do this. We need  
860 to move forward. We have a number of supportive advocacy  
861 groups out there.

862 I will just conclude by saying to you that let us do  
863 this. Let us do this for the women of this Nation. What  
864 happened on the Senate side to us last year was the insurance  
865 companies. We passed it 421 votes. That tells you something  
866 about the need. It tells you something about the support.  
867 Let us do it again in the House and let us make sure that our  
868 Senate colleagues do the same thing. Thank you so much for  
869 letting me speak to you.

870 [The prepared statement of Ms. DeLauro follows:]

871 \*\*\*\*\* INSERT 2 \*\*\*\*\*

|  
872 Mr. {Pallone.} Thank you, and thank you for your  
873 passion, really.

874 We only have about a minute left. I was going to  
875 suggest we come back, if that is okay. All right. We will  
876 reconvene after those votes with Congresswoman Wasserman  
877 Schultz. The Committee is in recess.

878 [Recess.]

879 Mr. {Pallone.} The Subcommittee will reconvene, and we  
880 had our Members' panel, and you ended up last, I guess. I  
881 apologize for that, Congresswoman Wasserman Schultz. But let  
882 me say, since we have a little time, thank you so much. You  
883 are like a hero. You really are. Or heroine, I guess, is  
884 the word. I mean, I don't know all the details but I  
885 remember the speech when you came to the Floor that one day  
886 and it was just amazing. All that you do, I don't know how  
887 you find the time, but thank you.

|  
888 ^STATEMENT OF DEBBIE WASSERMAN SCHULTZ

889 } Ms. {Wasserman Schultz.} Thank you so much, Mr.  
890 Chairman. I am happy to bat cleanup today for the Member  
891 panel, and Chairman Pallone and Ranking Member Deal when he  
892 comes back and the distinguished members of the Subcommittee  
893 that are here with us, it really is an honor to be here and  
894 to testify in front of the Health Subcommittee of Energy and  
895 Commerce, and Mr. Chairman, thank you very much for holding  
896 this hearing during Breast Cancer Awareness Month. I think  
897 that is a particularly important symbol. It is fitting that  
898 we review what is needed in the fight against breast cancer  
899 during this special month when, although we pay special  
900 attention to breast cancer awareness during the month of  
901 October, it is important that we focus on that awareness and  
902 help women pay attention to their breast health throughout  
903 the year.

904 Before I go further, I really want to give my deepest  
905 gratitude and thanks to the efforts of three of my  
906 colleagues, Sue Myrick, Rosa DeLauro and Donna Christensen,  
907 who embraced this legislation months ago before I publicly  
908 shared my own battle with breast cancer, and it was an honor  
909 to testify by the side of my friend and colleague, Rosa

910 DeLauro, and Sue, you are just superhuman. I think there was  
911 one day when you got 45 cosponsors for this bill in one small  
912 series of votes. It is hard for me to express how much I  
913 appreciate your support for me and the fact that I was able to  
914 share my story and talk to you about our mutual experience  
915 before I shared it with everyone else. Thank you very, very  
916 much. You have been there for me every step of the way.

917       Breast cancer strikes women from all backgrounds, all  
918 races, all ages and all ethnicities. It strikes black and  
919 white, rich and poor, those with access to quality health  
920 care and those without. But many women, too many women do  
921 not know their specific risk factors or their family history,  
922 and this is especially true with young women who see breast  
923 cancer as an older woman's disease. Many young women think  
924 breast cancer will never happen before they turn 40 but we  
925 know that young women can and do get breast cancer. In fact,  
926 each year nearly 24,000 women under 45 are diagnosed with  
927 breast cancer in the United States. While incidence rates of  
928 breast cancer are much lower in young women than older women,  
929 young women's breast cancers are generally more aggressive,  
930 they are diagnosed at a later stage and they result in higher  
931 mortality rates. After talking with many health care  
932 professionals, advocates in the breast cancer community and  
933 the Centers for Disease Control and Prevention, it became

934 clear that there was an urgent need to help build awareness  
935 among this often overlooked group. These conversations led  
936 to H.R. 1740, the Breast Health Education and Awareness  
937 Requires Learning Young Act, or the EARLY Act. This bill  
938 will empower young women to learn the facts, know their  
939 bodies, speak up for their health and embrace support. The  
940 truth is, we all need to be better informed about our own  
941 health. We must empower each other to know and reduce our  
942 risks.

943       Recently I learned I had more personal risks than I was  
944 aware of. Almost 2 years ago, as most of you know now, only  
945 6 weeks after a clean mammogram, I found a lump in my breast  
946 while doing a routine self-exam. My doctor diagnosed me with  
947 breast cancer when I was only 41. As a legislator, I have  
948 been in the fight against breast cancer for a long time. In  
949 Florida, I was the lead sponsor of the drive-through  
950 mastectomy law, the focus of Rosa's bill. I never dreamed I  
951 would need its protection myself. I thought I knew all of my  
952 risk factors. That is why I chose to perform self-exams and  
953 saw my doctor regularly. But after I was diagnosed, I  
954 learned I had more risk factors than I was aware of. I had  
955 no idea, for example, that as an Ashkenazi Jewish woman, I  
956 was five times more likely than the general population to  
957 have a BRCA1 or BRCA2 gene mutation. I didn't know that that

958 mutation gave me as much as an 85 percent chance of  
959 developing breast cancer during my lifetime. Too many young  
960 women are unaware of their risk.

961         The EARLY Act will give all young women the tools and  
962 information they need to take more control of their health.  
963 It will raise awareness of their personal risks and the  
964 importance of paying attention to their breast health. It  
965 will encourage young women to be familiar with the look and  
966 feel of their breasts. By knowing what feels normal, a young  
967 woman has a better chance of knowing when something feels  
968 different, and I can tell you that that is how it was for me.  
969 Because I did self-exams on a fairly regular basis, I was  
970 familiar enough with what my breasts normally felt like so  
971 that when I felt that lump, I knew it didn't belong there.  
972 The EARLY Act will teach young women and medical  
973 professionals about the importance of family history, warning  
974 signs of breast cancer and predictive tools such as genetic  
975 testing that can help some high-risk women make informed  
976 decisions about their health. It will also provide grants to  
977 organizations dedicated to supporting young women diagnosed  
978 with breast cancer. These grants will help young women  
979 tackle the unique challenges that they face like fertility  
980 preservation, body image and self-esteem as well as help them  
981 manage and understand their risks. And again, when a young

982 woman is diagnosed with breast cancer, I mean, at 28 years  
983 old, for example, if they don't even have a boyfriend and  
984 they are faced with breast cancer and having a double  
985 mastectomy and dealing with chemotherapy and facing their own  
986 mortality, on top of that having to think about how to  
987 preserve their fertility, that is a unique challenge that  
988 young women who are diagnosed with breast cancer face that  
989 older women simply do not, and younger women have to face  
990 many more years as survivors which presents in and of itself  
991 unique challenges.

992         So we have 371 cosponsors in the House including nearly  
993 all members of this Subcommittee and 34 cosponsors in the  
994 Senate. The EARLY Act has garnered broad public support from  
995 more than 40 advocacy and health organizations, many of whose  
996 representatives are behind me here today, and I just cannot  
997 thank these groups enough for their support, for their  
998 expertise and their guidance in helping to craft this  
999 legislation, but also for their personal support of me  
1000 because it has just been very moving and special for me.

1001         Some say that we shouldn't be talking to young women  
1002 about breast cancer at all because it might scare them.  
1003 Well, I find this quite simply patronizing. Young women and  
1004 providers can handle the truth. They can and should be  
1005 empowered with the knowledge that while only 15 percent of

1006 breast cancer cases are in women under 45, eight of these  
1007 women die every here in America. Having no information when  
1008 you are 35 about breast cancer and finding a lump in your  
1009 breast, that is what is really scary.

1010 Over the past year I have met with oncologists and other  
1011 health care professionals that work with breast cancer  
1012 patients, whether at MD Anderson Cancer Center in Houston,  
1013 the Dana Farber Cancer Institute at Harvard or the Cancer  
1014 Center at Memorial Regional Hospital in my district in  
1015 Florida, the message is clear: too often a diagnosis of  
1016 breast cancer is delayed or missed in young women. A Harvard  
1017 study of young women with breast cancer found 26 percent  
1018 delayed seeking medical attention and 27 percent experienced  
1019 a delay in diagnosis after seeking medical attention. This  
1020 means that more than half of young women are not receiving  
1021 the timely treatment that they need. We must do better. By  
1022 encouraging young women to know their bodies and their family  
1023 history and by teaching young women how to effectively talk  
1024 with their doctors and their doctors with them, we can  
1025 transform how we approach the fight against breast cancer.

1026 Every young woman that I know has the goal of becoming  
1027 an old woman. With the passage of the EARLY Act, we can help  
1028 more young women in America reach their goal and give them  
1029 powerful tools to take control of their own health for a

1030 lifetime. Thank you very much.

1031 [The prepared statement of Ms. Wasserman Schultz

1032 follows:]

1033 \*\*\*\*\* INSERT 3 \*\*\*\*\*

|  
1034 Mr. {Pallone.} Thank you so much. Really, you know,  
1035 even now you have given me a lot more insight into what needs  
1036 to be done and what we need to do, and I just want to stress  
1037 again, I know that there has been some discussion today about  
1038 what is in the health care reform bill and how some of these  
1039 bills relate and some parts of them actually are included,  
1040 but as I said earlier, this is a legislation hearing and so  
1041 we do intend to move the bills, and we will look and see what  
1042 is in the health reform and what isn't and take that all into  
1043 account.

1044 Ms. {Wasserman Schultz.} Mr. Chairman, I have been a  
1045 legislator for a long time. Any which way this bill becomes  
1046 law is fine with me. Thank you very much, and thank you to  
1047 the Committee staff because they have been an incredible  
1048 source of support and guidance as we move through the process  
1049 too. Thank you.

1050 Mr. {Pallone.} Take care.

1051 Now, what we are going to do with our second and third  
1052 panel is that the panelists have agreed, actually on their  
1053 own initiative, to put the two panels together, so we are  
1054 just going to have one panel. This way we can save time and  
1055 have a series of questions that way. So I would ask the  
1056 second and third panel members to come forward, if you would.

1057 Welcome. Let me say that the normal practice is that  
1058 Administration witnesses have a separate panel, which is why  
1059 Dr. Taplin from NIH would normally have had the second panel,  
1060 so I want to thank you for suggesting that you be with the  
1061 other panel, but I don't want anyone to think that that  
1062 prejudices what we do in the future. We understand that the  
1063 Administration is normally not part of another panel.

1064 So let me introduce everyone. Starting on my left is  
1065 Dr. Stephen Taplin, who is chief of the Applied Cancer  
1066 Screening Research Branch, Division of Cancer Control and  
1067 Population Science for the National Cancer Institute, which  
1068 is part of the National Institutes of Health. Then we have  
1069 Dr. Otis Webb Brawley, who is chief medical officer for the  
1070 American Cancer Society; Ms. Jenny Luray, who is president of  
1071 the Susan G. Komen for the Cure Advocacy Alliance; Debra L.  
1072 Ness, who is president of the National Partnership for Women  
1073 and Families; Dr. George W. Sledge, Jr., who Ballvé Professor  
1074 of Oncology at Indiana University Medical Center in the  
1075 Cancer Pavilion; Ms. Fran Visco, who is president of the  
1076 National Breast Cancer Coalition, and finally, Dr. Marisa C.  
1077 Weis, who is president and founder of Breastcancer.org. So  
1078 thank you all for being here, and I think you know we have 5-  
1079 minute opening statements that become part of the record. I  
1080 would like you to try to keep your comments to the 5 minutes

1081 if you could. You may get questions from the panel that you  
1082 have to get back to later in writing too, but we would like  
1083 you to try to answer the questions today.

1084           So we will start with Dr. Taplin from NIH. Thank you.

|  
1085 ^STATEMENTS OF STEPHEN TAPLIN, M.D., M.P.H., CHIEF OF THE  
1086 APPLIED CANCER SCREENING RESEARCH BRANCH, DIVISION OF CANCER  
1087 CONTROL AND POPULATION SCIENCE, NATIONAL CANCER INSTITUTE,  
1088 NATIONAL INSTITUTES OF HEALTH; OTIS WEBB BRAWLEY, M.D., CHIEF  
1089 MEDICAL OFFICER, AMERICAN CANCER SOCIETY; JENNIFER LURAY,  
1090 PRESIDENT, SUSAN G. KOMEN FOR THE CURE ADVOCACY ALLIANCE;  
1091 DEBRA L. NESS, PRESIDENT, NATIONAL PARTNERSHIP FOR WOMEN AND  
1092 FAMILIES; GEORGE W. SLEDGE, JR., M.D., BALLVÉ PROFESSOR OF  
1093 ONCOLOGY, INDIANA UNIVERSITY MEDICAL CENTER, CANCER PAVILION;  
1094 FRAN VISCO, J.D., PRESIDENT, NATIONAL BREAST CANCER  
1095 COALITION; AND MARISA C. WEISS, M.D., PRESIDENT AND FONDER,  
1096 BREASTCANCER.ORG

|  
1097 ^STATEMENT OF STEPHEN TAPLIN  
  
1098 } Dr. {Taplin.} Thank you, Mr. Chairman Pallone, and  
1099 Committee members. Thank you for the opportunity to speak  
1100 today. I have also provided a written document that  
1101 elaborates on my testimony with greater detail. As you have  
1102 heard, I am Dr. Stephen Taplin, the chief of the Applied  
1103 Cancer Research Branch at the National Cancer Institute.  
1104 Before coming to NCI, I spent 20 years as a practicing family  
1105 physician while also managing an organized breast cancer

1106 screening program and conducting screening research at Group  
1107 Health Cooperative, an integrated health plan in Seattle,  
1108 Washington.

1109         There is more than 50 years of research in breast cancer  
1110 screening and treatment that is now having a positive impact  
1111 on the lives of women. Research shows that the breast cancer  
1112 incidence increases markedly. Each year among 100,000 women,  
1113 1.4 cancers are diagnosed in the age group 20 to 24, but as  
1114 you can see here in figure 1, the rate rises to a peak of 454  
1115 in women ages 75 to 79. The benefit of research for these  
1116 women is that breast cancer death has fallen across all age  
1117 groups since 1975. Since 1990, the rate of decline has  
1118 accelerated and the annual percent reduction in mortality has  
1119 been a fairly consistent 2 to 3 percent per year over the  
1120 last 10 years. However, let me clear that I understand it is  
1121 not the research that changed the lives, it is the choices  
1122 women are making and the changes in therapy that physicians  
1123 that are implementing that has had the impact. The key is  
1124 those changes are guided by evidence from research.

1125         The mortality reduction we are seeing is due to both  
1126 improvements in treatment and improvements in screening. An  
1127 elegant set of modeling studies demonstrated approximately  
1128 half the reduction in mortality among women ages greater than  
1129 40 is due to screening, that in fact screening has become a

1130 large part of health in the United States since evidence from  
1131 randomized trials showed that mortality reductions were  
1132 possible. However, the integration of screening into care  
1133 has not been simple because the evidence was sometimes  
1134 ambiguous. The results from breast cancer screening trials  
1135 show less benefit for women ages 40 to 49. Furthermore, the  
1136 benefit appears much later in the lives of these women.  
1137 Ultimately, however, the results of randomized trials led to  
1138 national recommendations and increases in breast cancer  
1139 screening among average-risk women in the United States  
1140 beginning at age 40. The U.S. Preventative Services  
1141 Taskforce, as you have heard, suggests considering screening  
1142 every 1 to 2 years starting at age 40. Screening rates are  
1143 at about 66 percent within the last 2 years in the United  
1144 States today.

1145       It is clear that not everyone is at average risk. As  
1146 our knowledge of the genetic determinates of cancer has  
1147 grown, there has been increased concern regarding the  
1148 high-risk populations. The ACS has provided recommendations  
1149 that women at greater than 25 percent lifetime risk for  
1150 breast cancer should consider magnetic resonance imaging.  
1151 This is about 1 to 2 percent of women. These recommendations  
1152 are based on observational studies showing that technology  
1153 has a higher sensitivity in dense breast tissue.

1154 Unfortunately, it also shows more false positive tests than  
1155 occur with mammography. We need national work to show that  
1156 use of MRI in high-risk women actually affects mortality.  
1157 NCI is sponsoring studies on how to reduce the false-positive  
1158 testing with MRI but it continues to be a limitation. One  
1159 approach around the problem is to examine biomarkers and  
1160 biomarker profiles that may identify the lethal cancers or  
1161 become a screening test.

1162         Access across most races and ethnicities including  
1163 whites, women in lower socioeconomic groups are less likely  
1164 to be screened, in large part because they do not have access  
1165 to preventive care. People with less than 12 years of  
1166 education are one of the groups in the United States who have  
1167 not seen a significant drop in breast cancer mortality. The  
1168 Centers for Disease Control and Prevention has managed a  
1169 program to encourage access to screening among low-income  
1170 populations. That is a step towards addressing access.  
1171 Access to medical care is critical to screening because it is  
1172 a process, not a test. The screening process has multiple  
1173 steps as shown in figure 2, and these steps are managed in  
1174 clinical trials but not necessarily in usual practice in the  
1175 United States.

1176         To achieve the full potential of screening in the United  
1177 States, we must consider how to improve the entire process.

1178 We must also consider the effects of the process on all the  
1179 women, even those who will not get cancer. Some have argued  
1180 that healthy people should be very skeptical of screening  
1181 because most people will not have cancer even with a positive  
1182 test. Improving the screening process means finding better  
1183 tests and better diagnostic procedures. NCI is supporting  
1184 research in key areas relevant to optimizing the screening  
1185 process for breast cancer including risk estimation using  
1186 biomarkers as a genetic profile, comparative effectiveness  
1187 studies to evaluate MRI, 3D ultrasound and emerging  
1188 technologies and the comparison of alternative screening and  
1189 diagnostic strategies.

1190 In closing, I want to emphasize three points, that fewer  
1191 women have died of breast cancer because research has led to  
1192 progress in breast cancer screening and treatment, that the  
1193 research provides evidence for women and their physicians to  
1194 choose wisely among options they face but it is their  
1195 behavior that changes care and improves outcomes, and three,  
1196 that we have much more research to do to understand the  
1197 screening process, how to affect behavior, to identify  
1198 biomarkers of risk, cancer progression and treatment response  
1199 and to use all of this information to begin to personalize  
1200 screening.

1201 Thank you for the opportunity to testify.

1202 [The prepared statement of Dr. Taplin follows:]

1203 \*\*\*\*\* INSERT 4 \*\*\*\*\*

|

1204           Mr. {Pallone.} Thank you, Dr. Taplin.

1205           Dr. Brawley. I see your nametag says ``Brawler'' but it

1206 is Brawley, right? It is Brawley.

1207           Dr. {Brawley.} It is correct on this.

1208           Mr. {Pallone.} Thank you.

|  
1209 ^STATEMENT OF OTTO WEBB BRAWLEY

1210 } Dr. {Brawley.} Thank you, Mr. Chairman, and good  
1211 afternoon, distinguished members of the Committee. I am Dr.  
1212 Otis Brawley, the chief medical officer of the American  
1213 Cancer Society. I am a medical oncologist by training and a  
1214 practicing physician, and I am professor of hematology,  
1215 medical oncology, medicine and epidemiology at Emory  
1216 University. On behalf of the 11 million cancer patients and  
1217 survivors in America today, the American Cancer Society  
1218 thanks you for your continued leadership in the fight against  
1219 cancer and commitment to enacting comprehensive health care  
1220 reform this year.

1221 I greatly appreciate the opportunity to testify today on  
1222 federal initiatives to help fight breast cancer in the United  
1223 States. Dr. Taplin's comments were quite wise, by the way.  
1224 Breast cancer is an amazingly devastating disease. It is  
1225 also a very complicated disease. Too often we do a  
1226 disservice to women who we want to help by simplifying the  
1227 concepts of this disease with very simple message. Sometimes  
1228 simple messages actually end up doing harm. This year,  
1229 breast cancer will take the lives of approximately 40,000  
1230 women in the United States. This is particularly

1231 disheartening because we know that if every woman had access  
1232 to accurate information about the disease, good science-  
1233 driven early detection and quality and timely treatment, more  
1234 of them would survive this disease.

1235         Members of the Committee today quoted a lot of American  
1236 Cancer Society-generated statistics. One statistic generated  
1237 by the same ACS epidemiologist that I would like to quote is  
1238 the fact that with halfhearted approaches to breast cancer  
1239 from 1991 to 2005, 55,000 to 60,000 women's lives or deaths  
1240 were averted. We averted 55,000 to 60,000 breast cancer  
1241 deaths by really in essence halfheartedly approaching this  
1242 disease and not getting serious about it. At a time when at  
1243 least a third and indeed in the 1990s perhaps 50 percent of  
1244 women who should have been getting screened were not getting  
1245 screened, and even today a substantial number of women who  
1246 were screened and found with an abnormality get less than  
1247 good treatment for the disease. Unfortunately, not all women  
1248 have access to adequate health coverage with the public  
1249 health programs that have been proven to help save lives.  
1250 The consequences can be devastating in terms of prognosis.

1251         My testimony today will highlight four priority areas  
1252 that are essential to improved breast cancer outcomes in the  
1253 United States. Priority one: You must ensure access to  
1254 quality health care for all Americans. Our current health

1255 care system fails to meet the needs of far too many people.  
1256 Research has made clear that lack of health insurance can be  
1257 deadly. Studies have documented that uninsured breast cancer  
1258 patients are more likely to be diagnosed at a later stage of  
1259 disease and have lower survival rates than women who are  
1260 privately insured. That is a polite way of saying the  
1261 uninsured are more likely to die. Continued progress against  
1262 breast cancer requires that we give all cancer patients an  
1263 equal opportunity to battle this disease by making sure they  
1264 have access to quality and timely medical care.

1265       Priority two: We need to ensure that we apply what we  
1266 know about evidence-based prevention and early detection and  
1267 make these services available to all Americans. Breast  
1268 cancer is one of the few cancers early through evidence-based  
1269 screening tests. Absent these screenings, women are at risk  
1270 of being diagnosed at later stages of the disease when it has  
1271 spread and become more difficult and more expensive to treat  
1272 and chances of survival drop precipitously. Now is the time  
1273 to transform our current sick care system into one that also  
1274 focuses on prevention and wellness. This requires making  
1275 evidence-based and early detection services affordable and  
1276 accessible to all populations. Ironically, not doing so  
1277 increases our Nation's overall health care costs.

1278       Priority three: Clinical decisions must be patient-

1279 centered and made through strict rational and orthodox  
1280 interpretation of the most current scientific evidence. This  
1281 is particularly important in the context of a serious illness  
1282 like breast cancer or any cancer. As practitioners, we need  
1283 to strive to consistently do a better job of explaining the  
1284 evidence and the options for screening treatment and care as  
1285 understandably as possible to help patients make informed  
1286 decisions together with their health care teams.

1287         Priority four: Finally, we must do a better job of  
1288 addressing the health disparities that exist in our Nation.  
1289 Recent studies have shown differences in quality of care  
1290 provided among certain populations that of particular  
1291 concern. For example, Congresswoman Castor actually quoted a  
1292 study that I published together with colleagues last year  
1293 that showed that black women were five times more likely to  
1294 experience huge delays in starting breast cancer treatment  
1295 compared to white women. We also found that black women were  
1296 significantly less likely to receive appropriate surgery.  
1297 Seven and a half percent of black women and 1-1/2 percent of  
1298 white women with a locally staged potentially curable breast  
1299 cancer did not get breast surgery, research completed by  
1300 Halstead in 1903 that was not practiced in the year 2006. It  
1301 is well documented that insurance status and poverty are  
1302 principal determinates in cancer disparities. We simply must

1303 do a better job in providing access to appropriate early  
1304 diagnosis and cancer treatment services for all women.

1305         In closing, it is gratifying that since 1990 we have  
1306 been seeing a rise in the number of women surviving breast  
1307 cancer each year, and as I said, 55,000 to 60,000 deaths  
1308 averted. But that success is not enough. All women must  
1309 have access to accurate information, existing and future  
1310 early detection methods and quality treatment and care. The  
1311 number of deaths averted if all women who should have gotten  
1312 screening and should have gotten accurate diagnosis and  
1313 should have gotten accurate treatment, the number of deaths  
1314 averted would have easily doubled over that 55,000 to 60,000.

1315         The Society appreciates the leadership and commitment of  
1316 the Energy and Commerce Committee in helping eliminate  
1317 suffering from breast cancer through the work that will be  
1318 described today and through health care reform. My  
1319 colleagues at the American Cancer Society Cancer Action  
1320 Network, ACS CAN, and I look forward to working with you as  
1321 we look ahead to help create a world with less cancer.

1322         Thank you again for inviting me here today. I would be  
1323 happy to answer your questions, sir.

1324         [The prepared statement of Dr. Brawley follows:]

1325 \*\*\*\*\* INSERT 5 \*\*\*\*\*

|  
1326           Mr. {Pallone.} Thank you, Dr. Brawley.  
1327           Ms. Luray.

|  
1328 ^STATEMENT OF JENNIFER LURAY

1329 } Ms. {Luray.} Mr. Chairman and members of the Committee,  
1330 thank you for the opportunity to testify today about the four  
1331 breast cancer bills before your Committee. My name is  
1332 Jennifer Luray and I am president of the Susan G. Komen for  
1333 the Cure Advocacy Alliance and vice president of Government  
1334 Affairs and Public Policy for Susan G. Komen for the Cure.

1335 This year marks the 25th anniversary of National Breast  
1336 Cancer Awareness Month. It is an opportunity to reflect on  
1337 what we have accomplished and to work even harder to fight  
1338 the war on breast cancer. Before the Nation celebrated  
1339 breast cancer awareness, we practiced denial. We didn't talk  
1340 about breast cancer, didn't understand it, did little to find  
1341 out how to prevent and treat it. This was the world that  
1342 Susan Komen lived in when she heard those dreaded words at  
1343 age 33: ``You have breast cancer.'' Her sister, Nancy  
1344 Brinker, founded Susan G. Komen for the Cure, and a promise  
1345 made between two sisters to end breast cancer forever has  
1346 become the promise of millions. Thanks to events like the  
1347 Race for the Cure, we have invested almost \$1.5 billion in  
1348 cutting-edge research and community programs and have pledged  
1349 another \$2 billion over the next decade. The Komen Advocacy

1350 Alliance, the sister organization that I am proud to lead,  
1351 mobilizes a network of 250,000 advocates, men and women, at  
1352 the State and national level to promote important policy  
1353 change. Our promise is to leave few scientific opportunities  
1354 or community needs untouched.

1355         Yet, to make the most of these investments, we need to  
1356 first empower women to be advocates for their own health,  
1357 second, to expand access to health care, and third, to  
1358 improve the quality of care that women receive, and we need  
1359 the help of Congress to do that. That is why I am so pleased  
1360 to be here today, because of these bills before the Committee  
1361 helps us to move closer to these goals.

1362         I will first discuss the Breast Cancer EARLY Act, H.R.  
1363 1740. The Komen motto is that information empowers women to  
1364 be their own best advocates yet too many receive don't  
1365 receive information about breast cancer until their doctor  
1366 recommends their first mammogram at age 40, and that is just  
1367 too late for information. Each year, 25,000 women in this  
1368 country under age 45 are diagnosed with breast cancer, and  
1369 sadly, almost 3,000 under age 45 will die. That is  
1370 approximately 10 percent of all breast cancer diagnoses this  
1371 year, certainly not a trivial number. A carefully targeted,  
1372 evidence-based public health effort will inform young women  
1373 and importantly their providers that unfortunately breast

1374 cancer does occur in young women. It will help women to  
1375 establish good lifelong breast health habits like regular  
1376 exercise and to be empowered to seek care when they suspect  
1377 that something is wrong. It will also prevent fewer young  
1378 women with breast cancer from being overlooked by the medical  
1379 system and left undiagnosed until their disease is tragically  
1380 advanced. We have had an outpouring of support from young  
1381 women around the country for this bill. We are working with  
1382 the bill's sponsor to ensure that funding for the EARLY Act  
1383 won't come from existing funds for the CDC's breast and  
1384 cervical cancer program.

1385         Let us now turn to the Breast Cancer Patient Protection  
1386 Act, H.R. 1691. To be truly empowered, women also need to  
1387 the ability to impact decisions. That is why the Komen  
1388 Advocacy Alliance has consistently supported this bill by  
1389 Representatives DeLauro and Barton. Decisions concerning a  
1390 women's care after a complicated medical procedure should be  
1391 made between the woman and her doctor and not dictated by an  
1392 insurance company.

1393         H.R. 995, the Mammogram and MRI Availability Act,  
1394 introduced by Representative Nadler, brings us closer to the  
1395 second goal I mentioned, which is expanding access to health  
1396 care. At Komen, we believe that all women should have access  
1397 to recommended screenings including cancer survivors who need

1398 follow-up testing and surveillance. Guidelines recommended  
1399 by the American Cancer Society and the National Comprehensive  
1400 Cancer Network state that women at high risk should receive  
1401 annual screening mammograms and an MRI every year.  
1402 Importantly, women undergoing screening tests should do so in  
1403 conjunction with their doctor. When we talk about improving  
1404 access to care, we mean quality care for all women, our third  
1405 goal. So we commend Congresswoman Castor and Congresswoman  
1406 Christensen for their attention to the issue of disparities  
1407 in breast cancer. Low-income women should have access to the  
1408 same quality care as higher-income women so that they can  
1409 benefit from the same positive outcomes. Improving the  
1410 quality of cancer care across income, race and ethnicity has  
1411 long been a focus of Komen. We recently joined with the  
1412 American Society of Clinical Oncologists to collect data that  
1413 can be used for quality improvement. This type of data  
1414 collection is needed for any performance or quality-based  
1415 payment system.

1416 In addition to these bills specific to breast cancer, we  
1417 want to thank Congresswoman Capps for her leadership on two  
1418 comprehensive cancer bills, one to revamp research and the  
1419 other to improve care. The Komen Advocacy Alliance also  
1420 strongly supports the insurance reforms in H.R. 3200 that  
1421 would prevent patients from being denied coverage due to

1422 preexisting conditions, protect patients from high out-of-  
1423 pocket costs and dramatically improve access to mammograms.  
1424 Before Congress reconvened this fall, we asked our advocates  
1425 to share their personal experiences. Nearly 60,000 women and  
1426 men from around the country contacted their representatives.  
1427 Their heart-wrenching stories call out the need for health  
1428 care reform. Breast cancer patients turned down for  
1429 insurance turn destitute after paying for their care and turn  
1430 sicker because they couldn't afford screening or treatment.

1431         In conclusion, I want to thank you again for the  
1432 opportunity to testify before your Committee. As we mark the  
1433 25th anniversary of National Breast Cancer Awareness Month,  
1434 we take a hard look at what we have accomplished and where we  
1435 need to be. The stigma surrounding breast cancer in our  
1436 country is largely gone, a fact that makes us the envy of  
1437 women the world over. In the United States, more women are  
1438 being screened and living longer as a result, and we have  
1439 made progress on key scientific fronts. Yet, if we are one  
1440 day to end the suffering and death from breast cancer, we  
1441 must continue to make investments across the entire cancer  
1442 spectrum to prevent and better detect and treat the disease,  
1443 and we must always trust the women to be our partners in this  
1444 fight. Information empowers women to be their best  
1445 advocates.

1446           We look forward to working with you and our partners in  
1447 the cancer community as we continue this important race  
1448 forward. Thank you, Mr. Chairman.

1449           [The prepared statement of Ms. Luray follows:]

1450 \*\*\*\*\* INSERT 6 \*\*\*\*\*

|

1451 Mr. {Pallone.} Thank you.

1452 Ms. Ness.

|  
1453 ^STATEMENT OF DEBRA L. NESS

1454 } Ms. {Ness.} Good afternoon, Chairman Pallone, members  
1455 of the Subcommittee. Thank you for this opportunity to  
1456 testify.

1457 The National Partnership for Women and Families is a  
1458 nonprofit, nonpartisan organization with more than three and  
1459 a half decades of experience working on issues important to  
1460 women and families. Over the years we have brought together  
1461 a wide range of consumer voices to push for health reform  
1462 that would expand affordable coverage, help us get costs  
1463 under control, improve quality and reduce disparities. We  
1464 are very pleased to support the efforts of this Subcommittee  
1465 to enact comprehensive health reform this year. This is  
1466 truly a historic moment. For the first time in decades,  
1467 Congress is poised to enact comprehensive reform that would  
1468 vastly improve the lives and well-being of America's women  
1469 and families.

1470 We are pleased to endorse H.R. 3200 for many reasons.  
1471 It provides meaningful financial assistance to help low- and  
1472 moderate-income families purchase insurance. It ensures  
1473 adequate coverage and scope of benefits. It creates a health  
1474 insurance exchange with strong patient protections. It

1475 prevents insurers from denying or dropping people from  
1476 coverage because of their health status or raising rates  
1477 based on gender. Very importantly, it charts a pathway for  
1478 real delivery system reform. This pathway is key to ensuring  
1479 that the reforms we enact today are meaningful and  
1480 sustainable for the long haul. I believe H.R. 3200 lays the  
1481 groundwork for a system that over time will deliver better  
1482 care to patients and enable us to get more value for our  
1483 health care dollars. It does this by shoring up primary care  
1484 and encouraging better coordination through new payment  
1485 models and it creates the necessary foundation for those  
1486 models through things like comparative effectiveness  
1487 research, workforce development, better data collection and  
1488 quality measures and improvements.

1489       It is the development and use of quality measures that I  
1490 want to particularly focus on today, not just for breast  
1491 cancer care but for our system as whole. The use of measures  
1492 to generate performance information about provider  
1493 performance is critical to getting us to a system that at  
1494 some point delivers on the promise of the right care to the  
1495 right patients at the right time for the right reasons.  
1496 Without measurements, we can't know if the new models we are  
1497 putting in place are actually resulting in better patient  
1498 care. We can't assess whether we are really eliminating

1499 disparities. Without measurement, we can't tell if we are  
1500 using our health care dollars effectively. We can't  
1501 transition to a system that is based on value rather than  
1502 volume. Without good measures and good measurement and the  
1503 quality improvement that they enable, we simply cannot  
1504 achieve the high-quality, effective and equitable care that  
1505 patients need and deserve.

1506       Congresswoman Castor, you have clearly recognized the  
1507 importance of measurement in your bill, H.R. 2279, and we  
1508 applaud your commitment and leadership on women's health  
1509 issues. We share your goals of rewarding value over volume,  
1510 of incentivizing quality, of improving the patient's  
1511 experience of care and eliminating disparities, and we  
1512 particularly appreciate the provisions of your bill that move  
1513 us toward quality measurement and public reporting at the  
1514 individual provider level and that help us begin to align our  
1515 payment system so that we have incentives that encourage  
1516 better quality and practice that lives up to the best  
1517 standards of care. These elements are essential to building  
1518 a more effective delivery system and they should be integral  
1519 not just to care for breast cancer but to the broader reforms  
1520 that we all seek. We stand ready to work with you and your  
1521 colleagues to implement a pathway for these reforms but we  
1522 also urge that we do this in a way that benefits all patients

1523 no matter what their condition or diagnosis and in ways that  
1524 are going to generate accountability for all providers across  
1525 all settings. It is this vision that led the national  
1526 partnership to work with the Stand For Quality Coalition,  
1527 which is a broad group of about 200 health care stakeholders  
1528 that include consumers, purchasers and providers to issue a  
1529 set of recommendations that are now largely embodied in H.R.  
1530 3200. These recommendations call for a national  
1531 comprehensive strategy that includes setting priorities for  
1532 quality improvement and measurement, developing good measures  
1533 and then endorsing and maintaining those measures as national  
1534 standards, collecting and analyzing measurement data and then  
1535 using that data for quality improvement, for public reporting  
1536 and for payment. This broad coalition of stakeholders also  
1537 called for a multi-stakeholder consultative process to  
1538 provide input and make recommendations so that the  
1539 implementation of this strategy would engage in reflective  
1540 perspectives of all of us who have a stake in health care.

1541 So in closing, I want to say how pleased we are that  
1542 H.R. 3200 has incorporated these recommendations and I thank  
1543 the members of this Subcommittee for their leadership in  
1544 recognizing that a comprehensive quality strategy is the  
1545 critical foundation for health reform that is meaningful,  
1546 equitable and sustainable over the long term. Thank you.

1547 [The prepared statement of Ms. Ness follows:]

1548 \*\*\*\*\* INSERT 7 \*\*\*\*\*

|  
1549           Mr. {Pallone.} Thank you.  
1550           Dr. Sledge.

|  
1551 ^STATEMENT OF GEORGE W. SLEDGE, JR.

1552 } Dr. {Sledge.} Mr. Chairman Pallone, members of the  
1553 Subcommittee, thank you for the opportunity to submit  
1554 testimony today. My name is Dr. George Sledge. I am a  
1555 medical oncologist from Indianapolis who specializes in the  
1556 treatment of breast cancer. I also serve as professor of  
1557 medicine at Indiana University's Simon Cancer Center, and I  
1558 am president-elect of the American Society of Clinical  
1559 Oncology. ASCO's mission is to ensure that the highest  
1560 quality, evidence-based care is delivered to all people with  
1561 cancer during all stages of their disease. We are especially  
1562 pleased to speak at today's hearing as it focuses on the  
1563 cornerstones of ASCO's mission: cancer prevention, quality,  
1564 access to care and education.

1565 Many of us have been touched by breast cancer either  
1566 personally or through family members' or friends'  
1567 experiences. ASCO supports the underlying goals of all four  
1568 bills being discussed today and we urge this Committee to  
1569 ensure the resulting legislation is grounded in sound  
1570 scientific evidence. In today's testimony, I will focus on  
1571 three areas that span the continuum of cancer care: patient  
1572 access to appropriate screening, patient education and public

1573 awareness, and quality measurement in cancer care.

1574         The first is patient access to appropriate screening.  
1575 Studies have shown the value of cancer screening,  
1576 particularly mammography in women over the age of 40. ASCO  
1577 supports provisions that prohibit health plans from  
1578 establishing policies or barriers to medically appropriate  
1579 testing. While MRI is a highly sensitive test, we should not  
1580 overlook the potential risk of overdiagnosis that lead to  
1581 additional diagnostic tests including biopsy. Tests and  
1582 procedures cause anxiety and can lead to harms so we should  
1583 be very clear about the associated costs, risks and benefits.  
1584 The greatest utility for MRI appears to be for women who are  
1585 at high risk for breast cancer such as individuals who have a  
1586 strong family history. For women at high risk, detection of  
1587 abnormalities is less likely to result in false positive  
1588 findings. However, all women undergoing screening MRI should  
1589 be informed about the odds of false positive findings and the  
1590 potential adverse consequences of those findings.

1591         The second issue I will discuss is patient education and  
1592 public awareness. With respect to educating young women on  
1593 the causes and risks of breast cancer, such an endeavor must  
1594 be evidence based. An informed patient has a critical  
1595 advantage in cancer care treatment and the American Society  
1596 of Clinical Oncology has directed considerable resources and

1597 expertise to informing patients through our cancer.net  
1598 website.

1599         Finally, I would like to address quality measurement and  
1600 reporting, which is at the very core of ASCO's mission. More  
1601 than 500 oncology practices throughout the country  
1602 participate in ASCO's Quality Oncology Practice Initiative,  
1603 or QOPI, a system for practicing oncologists to submit  
1604 clinical data where practice-specific comparative data  
1605 reports are generated. QOPI allows oncologists to  
1606 systematically assess the quality of care they provide and  
1607 engage in data-driven practice improvement activities. The  
1608 majority of the 80 quality measurements in QOPI are  
1609 applicable to breast cancer patients and 14 are specific to  
1610 breast cancer treatment. QOPI together with the breast  
1611 cancer registry pilot made possible by generous support from  
1612 the Susan G. Komen For the Cure will provide tremendous  
1613 insight into how breast cancer patients receive care, where  
1614 improvements are needed and strategies for breast cancer  
1615 care. A project that tests well-designed quality measures in  
1616 breast cancer would move the field forward. However, such a  
1617 project must remain flexible, especially with respect to  
1618 public reporting of quality information. Studies of quality  
1619 performance suggest that the most important element is the  
1620 very active measuring and sharing outcomes with physicians.

1621 Value-based purchasing that reduces payment for low-quality  
1622 providers rather than rewarding high-quality providers may  
1623 have the unintended consequence of further stressing systems  
1624 that are already struggling. The development and testing of  
1625 quality measures would benefit from ASCO's long history of  
1626 work in this area. Some measures developed by ASCO have  
1627 already been endorsed by the National Quality Forum but the  
1628 number of NQF-endorsed measures for cancer is quite limited.  
1629 Significant work will be required to expand this portfolio so  
1630 that it includes the full range of measures required in H.R.  
1631 2279. ASCO would be delighted to provide its expertise in  
1632 this area.

1633 In closing, ASCO appreciates the tremendous thought and  
1634 attention the Subcommittee and sponsors of the four bills  
1635 have devoted to the care of women with breast cancer. We  
1636 look forward to working with you and our partners throughout  
1637 the cancer community to achieve the important goals set out  
1638 in these bills. Thank you very much.

1639 [The prepared statement of Dr. Sledge follows:]

1640 \*\*\*\*\* INSERT 8 \*\*\*\*\*

|

1641 Mr. {Pallone.} Thank you, Dr. Sledge.

1642 Ms. Visco.

|  
1643 ^STATEMENT OF FRAN VISCO

1644 } Ms. {Visco.} Thank you. Thank you, Chairman Pallone,  
1645 members of the Subcommittee. I appreciate very much the  
1646 opportunity to testify today on behalf of the National Breast  
1647 Cancer Coalition.

1648 I am a 22-year breast cancer survivor. I was diagnosed  
1649 when I was 39 years old. My son, David, was 14 months old.  
1650 I was a partner in a law firm in Philadelphia and I was  
1651 fortunate that I became involved with a group of women who  
1652 launched the National Breast Cancer Coalition and I soon left  
1653 my law practice to devote my life to our mission to eradicate  
1654 breast cancer.

1655 We are a coalition of organizations from across the  
1656 country. Our board of directors is a board of 25 of these  
1657 organizations representing the diversity that is breast  
1658 cancer from the Women of Color Support Group, to Nueva Vida,  
1659 to the Alamo Breast Cancer Coalition, to the California  
1660 Alliance of Breast Cancer Organizations. Our national  
1661 grassroots network consists of representatives of many  
1662 different organizations. We set priorities. We educate our  
1663 members to understand the language and the concepts of  
1664 science. We know that women are quite capable of

1665 understanding these issues, of accepting the truth no matter  
1666 how difficult that may be, and of speaking up for themselves.  
1667 We critically analyze information. We critically analyze  
1668 public policies before we set our priorities and before we  
1669 take positions, and we have but one agenda and that is to  
1670 eradicate breast cancer.

1671 I know the Committee today is focusing on a number of  
1672 bills specific to breast cancer and we have submitted  
1673 analyzes of some of those bills to members, and I will submit  
1674 them for the record. But what I want to focus my remarks on  
1675 today is our number one priority, and that is the bill that  
1676 we believe will have the largest impact for all women at risk  
1677 of and all women who have received a diagnosis of breast  
1678 cancer and that is guaranteed access to quality health care  
1679 for all. We followed our process of research of critical  
1680 analysis. We spent several years educating our grass roots,  
1681 looking at various health care systems, reading the  
1682 literature, researching the system, and we developed our  
1683 framework which was submitted with our written testimony to  
1684 support guaranteed access for all, educated patient  
1685 participation at all levels of the system, shared  
1686 responsibility and benefits based on evidence. We strongly  
1687 support comparative effectiveness research because we believe  
1688 that it is necessary to help ensure quality and affordable

1689 health care for all. We need a high level of evidence for  
1690 doctors and patients to choose which care is appropriate, for  
1691 whom and under what circumstances. In addition, our  
1692 framework calls for a significant number, and that is 25  
1693 percent of educated patient and consumer member on all  
1694 committees, commissions and boards involved in health care  
1695 including those established to review and assess the best  
1696 evidence-based treatment options.

1697         We commend the Committee for its work on H.R. 3200,  
1698 which achieves many of the benchmarks set forth in our  
1699 framework, and we are pleased to endorse that bill and we  
1700 look forward to working with you to ensure that all  
1701 individuals have access to the comprehensive quality care  
1702 they deserve, quality care they need. Everyone should have  
1703 access and it must be affordable, not just for the federal  
1704 budget but to people. It must be affordable to individuals.  
1705 We very much appreciate your interest and support of our  
1706 shared goal to save lives and to end breast cancer. You have  
1707 the power to make a real difference for all of us, and we  
1708 know how complicated these issues are, how difficult your  
1709 task is. We know how complex breast cancer is and how  
1710 careful we all have to be to make certain that what we are  
1711 doing is the right thing in terms of women's lives.

1712         There are too many unfortunate examples of policy

1713 messaging and beliefs that have taken hold when there was in  
1714 fact no real evidence behind it, and these actions resulted  
1715 in harm to women. My written testimony describes them from  
1716 bone marrow transplants to breast self-exams and hormone  
1717 replacement therapy to the misuse of statistics by opponents  
1718 to health care reform that are looking inappropriately at  
1719 survival statistics that are outdated from different  
1720 countries. All of that has been submitted with my written  
1721 testimony.

1722 I know firsthand the horror of breast cancer and I see  
1723 that horror over and over again for too many women of all  
1724 ages, all races, all walks of life. That is why we are so  
1725 firmly committed to the evidence-based approaches, to our  
1726 passionate commitment to eradicating breast cancer.

1727 I want to take a moment to talk about Carolina  
1728 Hinestrosa, a strong, passionate, unbelievable activist. She  
1729 was the executive vice president of the National Breast  
1730 Cancer Coalition. She founded Nueva Vida, a national support  
1731 group for Hispanic women with breast cancer. She was  
1732 diagnosed 15 years ago at the age of 35 and then again 6  
1733 years ago. She died in June of a soft-tissue sarcoma, a  
1734 result of her treatment for breast cancer, not breast cancer,  
1735 her treatment for breast cancer, just one more story of how  
1736 complex this disease is, how complicated the issues are. I

1737 dedicate my testimony and my work to her memory, and I thank  
1738 you again.

1739 [The prepared statement of Ms. Visco follows:]

1740 \*\*\*\*\* INSERT 9 \*\*\*\*\*

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1741 Mr. {Pallone.} Thank you, Ms. Visco.

1742 Dr. Weiss.

|  
1743 ^STATEMENT OF MARISA C. WEISS

1744 } Dr. {Weiss.} Thank you, Chairman Pallone, Subcommittee  
1745 members and other panelists. It is a true privilege for me  
1746 to be here today to talk about breast health and breast  
1747 cancer issues that have been my core professional focus and  
1748 driving mission for over 20 years, but more importantly,  
1749 these issues directly affect about half the United States  
1750 population and the rest of us who care for them.

1751 My name is Dr. Marisa Weiss. I am a breast oncologist  
1752 and founder and president of the nonprofit Breastcancer.org.  
1753 We are the world's most utilized online resource for breast  
1754 health and breast cancer information, reaching 8 million  
1755 people annually. As a doctor, I have had the honor taking  
1756 care of thousands of women with breast cancer and have seen  
1757 up close its devastating effects, and our laws govern how I  
1758 can best care for the unique needs of each individual that  
1759 comes to me.

1760 Everyone here knows how much is at stake. The breasts  
1761 are the favorite place for cancer to occur in women, often in  
1762 their prime of their lives and when these women are most  
1763 indispensable to so many. The bills before the Committee  
1764 today represent critical ongoing efforts to improve diagnosis

1765 and patient care. I would like to start with the EARLY Act.  
1766 I believe this legislation will do much to advance public  
1767 health efforts and combat the threat of breast cancer, and I  
1768 commend Congresswoman Wasserman Schultz for her leadership.  
1769 There are concerns that outreach to young women will produce  
1770 more harm than good by creating the fear of breast cancer,  
1771 but what we have found is that fear already widely exists.  
1772 Information about breast cancer is pervasive. Young women  
1773 like the rest of us are bombarded by breast cancer messaging  
1774 aimed at adult women. To better understand the impact,  
1775 Breastcancer.org conducted a research project with 3,000  
1776 girls ages 8 to 18 across the country. Consistently, nearly  
1777 30 percent of girls feared that they may have had breast  
1778 cancer. It was triggered by breast pain, a diagnosis in  
1779 someone close to them, or mistaking the changes of normal  
1780 breast development for signs of breast cancer. Over 70  
1781 percent of girls have someone close to them who has been  
1782 diagnosed, a mother, grandmother, best friend's mom, teacher  
1783 or neighbor, and when breast cancer diagnosis strikes this  
1784 close to home, their fears were magnified. Many young women  
1785 think breast cancer messages in the media targeted to mature  
1786 women directly apply to them as well, but they simply don't  
1787 have the resources to understand the meaning and relevance of  
1788 these critical issues nor do they have the dialog skills or

1789 opportunities to discuss their fears or clarify breast cancer  
1790 misinformation. Only 47 percent of the girls had talked to a  
1791 parent, 40 percent to a doctor.

1792         To resolve unrealistic fears, young women in this era  
1793 need accurate information and reassurance that age-  
1794 appropriate and scientifically grounded education can arm  
1795 them with the facts of what is normal and what is not,  
1796 empower them to take charge of their breast health. It is  
1797 these girls during the ages of 8 to 18 and into their 20s  
1798 that are using what they eat, what they drink, what they  
1799 breathe in, medicines they take, personal products that they  
1800 use to build their breast tissue, laying down the foundation  
1801 of their future breast health. It is at this early point  
1802 also that young women are establishing their lifelong  
1803 behavioral patterns.

1804         Concerns have been raised about the value of education  
1805 outreach to low-risk populations in the absence of modifiable  
1806 risk factors, and we know how complex a disease breast cancer  
1807 is with multiple causes, but most of these risks for breast  
1808 cancer don't begin at age 45. Rather, they accumulate over a  
1809 lifetime beginning at conception. There are periods when  
1810 breast cells are hypersensitive to internal and external  
1811 environmental insults: the first trimester of pregnancy, the  
1812 4 to 10 main years of breast organogenesis between

1813 adolescence and the 20s, as well as the stretch of time  
1814 leading up to a woman's first full-time pregnancy when breast  
1815 cells are highly active and immature. So the behaviors of  
1816 women under age 45 impact not only their own breast health  
1817 but the future breast health of their daughters through  
1818 pregnancy and modeled behaviors. Some risks are modifiable  
1819 and some are not but even the tiny risks can combine and  
1820 really add up, particularly during these sensitive times. An  
1821 example of a modifiable risk factor is the obesity epidemic  
1822 across the United States associated with an increase in risk  
1823 of breast cancer in adult women. Extra fat makes extra  
1824 hormones that could stimulate extra breast cell growth. In  
1825 addition, fat stores hormonally active pollutants that are  
1826 lipophilic such as bisphenol A, atrazine, dioxins,  
1827 nonylphenols, which could potentially stimulate unhealthy  
1828 breast cell growth. And moreover, obesity in childhood  
1829 predicts for obesity in adults and obese mothers are more  
1830 likely to raise obese daughters. And contrary to the claim  
1831 that proven breast cancer risks can't be modified, our  
1832 obesity epidemic is doing just that, by accelerating the age  
1833 of menarche. Early education and behavioral modification  
1834 that increases athletic activity and health weight management  
1835 early enough could postpone the onset of puberty, and lessons  
1836 learned from the EARLY Act programs will benefit current and

1837 future generations since it is the women under the age of 45  
1838 who are in their prime childbearing and parenting years.

1839 Another example is the opportunity to provide breast  
1840 cancer risk reduction strategies to high-risk women. In the  
1841 EARLY Act, the 5 to 10 percent of breast cancers due to an  
1842 inherited breast cancer genetic abnormality, over 13,000 per  
1843 year, would more likely be identified, giving these women a  
1844 greater chance to reduce the risk of breast cancer by as much  
1845 as 90 percent with prophylactic mastectomies or 50 percent  
1846 with anti-estrogen therapies.

1847 It is important that we impart this knowledge along with  
1848 what we, the scientific and medical community, know are not  
1849 risk factors for breast cancer. Fear certainly breeds myths,  
1850 and in our survey many young women believe that only their  
1851 mother's family history is important and that breast cancer  
1852 skips generations. They also were fearful that they could  
1853 have caught breast cancer from their mothers during pregnancy  
1854 and breastfeeding. Education can change attitudes, knowledge  
1855 and behaviors. We do a disservice to this and future  
1856 generations by neglecting to provide this information and  
1857 facilitate this dialog.

1858 I am also here today in full support of the Breast  
1859 Cancer Patient Protection Act, the Mammogram and MRI  
1860 Availability Act, and Eliminating Disparities in Breast

1861 Cancer Treatment. I am prepared to answer any questions  
1862 about the medical content.

1863           And in conclusion, I thank the chairman, the  
1864 Subcommittee and the panel for giving me the opportunity to  
1865 speak to you today. Thank you.

1866           [The prepared statement of Dr. Weiss follows:]

1867 \*\*\*\*\* INSERT 10 \*\*\*\*\*

|  
1868 Mr. {Pallone.} Thank you, Dr. Weiss.

1869 Now we will have questions from the members, and I will  
1870 start myself, and I wanted to ask Dr. Taplin some questions  
1871 initially.

1872 In fiscal year 2007, the National Cancer Institute  
1873 invested nearly \$600 million in breast cancer research. I  
1874 understand the Institute devoted roughly the same amount of  
1875 resources towards research on this topic in 2008. Can you  
1876 describe, Dr. Taplin, the activities that NIH is supporting,  
1877 understand how women can actually prevent breast cancer in  
1878 the first place and how is NIH investing in research into  
1879 improved breast cancer screening as well as into treatment of  
1880 breast cancer once it has been diagnosed, in less than 2  
1881 minutes? Whatever you can do.

1882 Dr. {Taplin.} There are many studies related to breast  
1883 cancer at NCI. As you have already noted, we had \$572.6  
1884 million and 2,146 studies at NCI in fiscal year 2008. Those  
1885 are concentrated in several areas but the ones relevant to  
1886 your question are prevention, early detection and treatment.  
1887 We spent approximately \$27 million on prevention, \$54 million  
1888 on early detection and \$169 million on treatment studies, so  
1889 all of those are relevant to your question. I think probably  
1890 the most interesting piece, and there are several, and many

1891 places we can go among the 2,146 studies we did. The most  
1892 important, I think, is the Breast Cancer and Environmental  
1893 Research Act, which came from you folks and resulted in a  
1894 center, a set of centers to look at basic--the relationship  
1895 between environment and biology of young women's breast  
1896 development, and so there are biologic studies in women,  
1897 there is epidemiology study in young women and there is also  
1898 a group of people looking, academicians and educators,  
1899 looking at how you communicate these issues to women and to  
1900 young women especially so that we can begin to adapt those  
1901 message to the population that we are targeting. Those are  
1902 some of the areas we are working on.

1903 Mr. {Pallone.} All right. Thank you.

1904 Dr. Brawley, I wanted to ask you, the U.S. Preventative  
1905 Taskforce recommends that women over 40 have annual or  
1906 biannual mammograms. Your organization recommends annual  
1907 mammograms for women over 40 and clinical breast examinations  
1908 for women in their 20s or 30s. So unless a woman under 40  
1909 has an identified risk factor, there is no recommendation  
1910 that she get a mammogram. Obviously, you know, this relates  
1911 to Congresswoman Wasserman Schultz's legislation. Would you  
1912 elaborate on the challenges for women under 40 and what can  
1913 we do for these women to detect their cancers as early as  
1914 feasible?

1915 Dr. {Brawley.} Yes, sir. Thank you for the question.  
1916 Part of the answer to your question is mammography is a  
1917 terrible test for women who have younger breasts and denser  
1918 breasts. It is a terrible test for two reasons. Number one,  
1919 it is very difficult for the radiologist to actually make an  
1920 interpretation of that X-ray because of the breast density,  
1921 and number two, radiation does cause some cancers and causes  
1922 cancers in young breasts that are more active in terms of  
1923 biology. So if you actually were to give radiation to the  
1924 breasts of, say, 10,000 women who are under the age of 20 and  
1925 do it on an annual rate, there are some people here--I am not  
1926 one of them--but they can calculate how many breast cancers  
1927 we will ultimately manufacture. Now, in randomized clinical  
1928 trials of women who are older, in their 40s, 50s and 60s, we  
1929 have evidence that mammography clearly saves lives in  
1930 screening, so what we like to do is, if a woman has a mass  
1931 and she is in her 20s or 30s, if she finds the mass or if  
1932 someone finds it on clinical exam, a clinician, be it a nurse  
1933 practitioner or a physician, then perhaps doing a mammogram  
1934 is appropriate in that one particular individual. If you  
1935 have someone who is at very high risk, perhaps the mammogram  
1936 is appropriate or perhaps an MRI is, but to do mammography,  
1937 mass mammography in the United States in younger women, it  
1938 would be literally public health malpractice because we would

1939 actually manufacturing some breast cancers.

1940 Mr. {Pallone.} Okay. I was going to ask a third  
1941 question but I don't have that much time left, so I will move  
1942 to other members. The gentleman from Georgia, Mr. Gingrey.

1943 Mr. {Gingrey.} Mr. Chairman, thank you, and I will ask  
1944 all of the panelists, and I thank you for being here, the  
1945 same question, and I will start with Dr. Taplin. Some have  
1946 said that this bill will spread fear of breast cancer among  
1947 women who shouldn't be concerned at such a young stage of  
1948 their life. As physician, I believe that arming patients  
1949 with medical information is a good practice as long as the  
1950 message is, of course, well crafted and well delivered. Do  
1951 you have any concerns that keeping this demographic well  
1952 informed will cause more harm than good?

1953 Dr. {Taplin.} That is an excellent question. I think  
1954 the problem is that we don't have the evidence to give you  
1955 the answer. The problem is that there is some evidence out  
1956 there that there is a U-shaped curve, that there is a perfect  
1957 amount of fear. A little bit of fear may be helpful. A  
1958 little bit too much fear may be harmful, and we don't really  
1959 know where the balance is between those things and we don't  
1960 know enough about messaging from my standpoint to know what  
1961 the answer is to the question you are posing, so that is part  
1962 of why we are sponsoring the study that I have already

1963 mentioned.

1964 Mr. {Gingrey.} Dr. Brawley?

1965 Dr. {Brawley.} Dr. Gingrey, part of the American Cancer  
1966 Society's early concern about this bill was that it wasn't  
1967 clear who was going to create the messages that were going to  
1968 be conveyed to the population. Now that it is very clear  
1969 that a committee of scientists appointed by the director of  
1970 the CDC will be those that craft the messages that should be  
1971 conveyed, we feel very comfortable with educating the  
1972 population because we have some assurances that the messages  
1973 will be created by experts. So yes, I am agreeing with you  
1974 and I think that the messages that would be conveyed through  
1975 the EARLY Act would be message that would be scientifically  
1976 valid. Now, you are correct that the messaging to  
1977 individuals, be they youth or be they people in their 50s, is  
1978 sort of like a T1 line. The more health messages that you  
1979 put forth, you diminish all the other health messages.  
1980 Currently, the EARLY Act, as I see it, allows for messages  
1981 about diet, messages about exercise and nutrition, and it  
1982 actually may be more than a breast health act, much more a  
1983 health act because it is going to--if the messages are  
1984 received appropriately, it is going to prevent diabetes and  
1985 heart disease which actually, by the way, kill more people in  
1986 their 30s and 40s, females in their 30s and 40s, than breast

1987 cancer.

1988 Mr. {Gingrey.} Ms. Luray?

1989 Ms. {Luray.} Congressman, we agree with Dr. Brawley.

1990 We are pleased how the bill has evolved over time. One study  
1991 of young survivors found that 40 percent didn't believe that  
1992 young women could even get breast cancer, so part of what we  
1993 are looking for is a very targeted campaign that lets women  
1994 know that while it is a very small risk, it is possible so  
1995 that if they feel that lump, they don't ignore it, or if they  
1996 go into their doctor's office and they say I feel like I have  
1997 a lump and the doctor says oh, it is just dense breast  
1998 tissue, don't worry about it, they can't pursue their  
1999 concern, and again, based on factual information pulled  
2000 together by the appropriate sources.

2001 Mr. {Gingrey.} Ms. Ness?

2002 Ms. {Ness.} I will just reinforce what my colleagues  
2003 here have said. I think we can't underscore enough the  
2004 importance of basing what we do on evidence, and we need the  
2005 research to tell us what makes us both in terms of medical  
2006 practice but also in terms of how we educate and increase  
2007 awareness.

2008 Mr. {Gingrey.} And Dr. Sledge?

2009 Dr. {Sledge.} Well, I think we all agree that knowledge  
2010 is power, but it is only powerful to the degree to which it

2011 is accurate and we can act on it, and I think careful  
2012 evidence-based data is actionable. The problem in younger  
2013 women, to be honest, is that a lot of what we don't know  
2014 exceeds what we do in terms of prevention for young women in  
2015 terms of early diagnosis, in terms of the health habits for  
2016 these women. So I think physicians and all of us need to be  
2017 very careful about pretending more than we currently know.

2018 Mr. {Gingrey.} Ms. Visco?

2019 Ms. {Visco.} Well, I couldn't have said it better than  
2020 Dr. Sledge did. I think it is very important that message  
2021 that we give out are based on evidence, that are factually  
2022 correct and that there is something you can actually do about  
2023 that information, but I want to make clear that the evidence  
2024 of harms that some people are concerned about and we are  
2025 concerned about certainly with giving messages about breast  
2026 cancer to millions and millions of healthy women, the vast,  
2027 vast majority of whom will never get breast cancer, is also  
2028 the distinct and clear possibility that has been shown in  
2029 clinical trials of unnecessary biopsies, that young women are  
2030 going to feel things in their breasts, they are going to have  
2031 biopsies. Those biopsies can result in infections and in  
2032 further harm. So it is not just the issue of anxiety. That  
2033 is why it is so incredibly complex.

2034 Mr. {Gingrey.} Dr. Weiss, before you respond, and as a

2035 breast cancer surgeon and having treated many, many patients,  
2036 how young do you think we really should give this information  
2037 to young women? At what age do you start doing that?

2038 Dr. {Weiss.} Well, this information becomes--it is  
2039 important to deliver it when it is most relevant, and we find  
2040 that girls are going through puberty earlier and earlier  
2041 these days and their breasts are very much on their minds. I  
2042 think the power of education is not just delivering education  
2043 along the way but correcting this massive misinformation that  
2044 is out there. Our surveys have shown that over 20 percent of  
2045 girls think that antiperspirant use, getting bumped in the  
2046 breast, infection, drug use, drinking coffee, wearing a bra,  
2047 an underwire bra, increase the risk of breast cancer, and  
2048 without the correct information that is well established  
2049 today. So I do think that when you replace myths with facts  
2050 that you do free these girls of some of the anxiety they have  
2051 about growing up and going from a big girl to a young woman  
2052 and a young woman to a mature woman, and I think that that is  
2053 going to make them more engaged in proactive healthy  
2054 behaviors through their life, and while they are in high  
2055 school and college, they are in educational institutions,  
2056 they are within a system where knowledge delivery is--

2057 Mr. {Gingrey.} So educating them as teenagers but not  
2058 necessarily preteens?

2059 Dr. {Weiss.} Well, we have found that a lot of  
2060 misinformation, fears and questions present themselves upon  
2061 adolescence, and whether or not you want to go back that  
2062 early is a question that has to be studied, but those  
2063 questions certainly exist, and they are inadequately  
2064 addressed right now in current health classes within middle  
2065 schools and high schools.

2066 Mr. {Gingrey.} Mr. Chairman, thank you very much, and  
2067 thank all the panelists. I appreciate your response.

2068 Mr. {Pallone.} Thank you.

2069 Ms. Castor.

2070 Ms. {Castor.} Thank you, Mr. Chairman, and thank you  
2071 all. Your testimony was very insightful, everyone.

2072 Ms. Luray, I would like to thank you and the Susan G.  
2073 Komen for the Cure Advocacy Alliance for extending your  
2074 support to my Eliminating Disparities in Breast Cancer Act  
2075 since it was first introduced last Congress, and I would like  
2076 to return the thanks and commend you all for everything that  
2077 you have done to raise awareness about disparities in access,  
2078 access to screening, access to quality care and treatment.  
2079 The work you have done both with the American Society of  
2080 Clinical Oncologists and the Metropolitan Chicago Breast  
2081 Cancer Taskforce to reduce disparities is very commendable.  
2082 Could you discuss what you believe we can do further to

2083 educate women about the types of treatment that they should  
2084 look to receive after diagnosis so that women are not in the  
2085 dark and are empowered to take control of their health and  
2086 diagnosis? And please explain how moving forwards towards  
2087 rewarding providers for quality care and ensuring that  
2088 providers are not rewarded for inadequate care will help to  
2089 reduce disparities in treatment.

2090 Ms. {Luray.} Thank you, Congresswoman, and we  
2091 appreciate your leadership as well. I would like to take a  
2092 minute just to talk briefly about our partnership with the  
2093 Metropolitan Chicago Breast Cancer Taskforce because I think  
2094 it is partnerships like this that will give us the data that  
2095 then can be modeled by other community-based programs to  
2096 promote the type of quality breast cancer care you are  
2097 talking about across common and racial ethnic lines. In  
2098 Chicago, the breast cancer mortality rate for African-  
2099 Americans is even worse than in the rest of the country.  
2100 African-American women in Chicago have a 68 percent higher  
2101 mortality rate than white women do, and the taskforce that we  
2102 are involved in and are supporting developed an action plan  
2103 for three main causes of the disparity, and it is almost like  
2104 a tragic Rube Goldberg image because first of all, they have  
2105 to get access to mammography, and that is either physical,  
2106 where it is, how do you get there, and economic, can they

2107 afford it. But then they have to make sure that is of high  
2108 quality, and we as providers and advocates need to make sure  
2109 that that mammography is of high quality. And then they have  
2110 inadequate access to treatment, and then you have to ask the  
2111 same questions about their treatment, is the treatment that  
2112 they are getting at the same level of evidence and the same  
2113 level of quality that higher-income women are getting. So  
2114 again, there are so many barriers that need to be addressed  
2115 in terms of ensuring that this disparity in care does not  
2116 continue in communities. But we are very hopeful that what  
2117 we are doing in Chicago and what we are funding in  
2118 communities across the country can help to promote a very  
2119 high-quality breast cancer treatment program.

2120 Ms. {Castor.} Have you targeted other communities  
2121 besides Chicago?

2122 Ms. {Luray.} Yes, we have, and I would be happy to  
2123 share that information with your staff.

2124 Ms. {Castor.} Terrific.

2125 The American Cancer Society found in 2007 that certain  
2126 additional screenings after diagnosis and initial treatment  
2127 are not equally administered among patients, particularly  
2128 tests to ensure that cancer has not spread to nearby lymph  
2129 nodes. Maybe Dr. Brawley, can you share with us, have you  
2130 found that additional screenings after treatment that are

2131 considered essential are not always accessible? I think you  
2132 testified to that account.

2133 Dr. {Brawley.} Yes, ma'am.

2134 Ms. {Castor.} To what do you think that we can  
2135 attribute the fact that some providers simply are not  
2136 universally screening patients for potential spread of their  
2137 cancer to other areas of the body?

2138 Dr. {Brawley.} I think the likelihood--I don't have a  
2139 study that I can quote for you but I can tell you as someone  
2140 who has practiced medicine, the likelihood is that there can  
2141 be a couple different reasons, and what we are talking about  
2142 there is follow-up exams after treatment to see if the  
2143 disease has come back. Sometimes the physicians simply  
2144 forget, which is unfortunate on the part of the physicians.  
2145 Sometimes the patients are advised to get the test or it is  
2146 prescribed and they don't go and get the test. Sometimes,  
2147 and this is the more common problem, there is an  
2148 affordability problem, copays and other things that people  
2149 are just unable to come up with, even if insured, and I am  
2150 actually much more concerned very frequently about the  
2151 insured individual who doesn't have very good insurance than  
2152 even the uninsured individual because quite a few people  
2153 today--I just saw a figure, more than 60 percent of personal  
2154 bankruptcies are due to health care costs. Quite a few

2155 individuals with breast cancer who need to get a chest X-ray  
2156 or even just a simple liver function test that might cost \$80  
2157 simply can't afford the continued copays over time so they  
2158 don't get those therapies.

2159 Ms. {Castor.} Thank you, Mr. Chairman.

2160 Mr. {Pallone.} Thank you.

2161 The gentlewoman from Ohio, Ms. Sutton.

2162 Ms. {Sutton.} Thank you, Mr. Chairman. Before I begin,  
2163 I could ask unanimous consent to enter into the record  
2164 testimony from Lifetime Networks.

2165 [The information follows:]

2166 \*\*\*\*\* COMMITTEE INSERT \*\*\*\*\*

|  
2167 Mr. {Pallone.} Without objection, so ordered.

2168 Ms. {Sutton.} Thank you. And before I turn to the  
2169 panel, Mr. Chairman, if I could, I would also just like to  
2170 recognize Kathy and Lee Giller, who are here from Akron,  
2171 Ohio, my district, and they are town for the 3-day Susan G.  
2172 Komen Walk, and Kathy was the number one fundraiser from  
2173 Cleveland this year, and we are proud to have her here with  
2174 us.

2175 As for the panel, thank you very, very much for your  
2176 testimony, and it is hard to sit here without thinking about  
2177 the people that we have known in our lives who have suffered  
2178 from breast cancer, some who have been lost, some who are  
2179 fighting the fight now, and of course, wondering about those  
2180 who may encounter this battle in the future. Several of you  
2181 in your remarks and in your testimony, you stress the need  
2182 for the access to quality, affordable health care. Ms.  
2183 Visco, you talk about quality, affordable health care for  
2184 all. I appreciate that, and I concur. Dr. Brawley, you also  
2185 talked a lot about the need to get health care for women.  
2186 And Dr. Weiss, one of the things that you said that was  
2187 striking to me and I think it is important is, you talked  
2188 about the unique needs of patients because not always does  
2189 one size fit all on this issue. And as I sit here, one of

2190 the people who comes to mind was a woman who I knew 10 years  
2191 ago when I was working on these issues in the State  
2192 legislature, and her name was Linda. She had breast cancer.  
2193 Her mother had had breast cancer, her aunt. It was very  
2194 pervasive in her family. Her doctor wanted to treat her  
2195 aggressively because of the family history, a doctor attached  
2196 to an institution that is of high renown when it comes to  
2197 treatment, and the insurance company said no, we are not  
2198 going to pay for coverage of that treatment. Her treatment  
2199 was delayed because she had to raise money for the treatment.  
2200 She ultimately succumbed to cancer. I went to her funeral  
2201 and I listened to her young daughter get up and give a report  
2202 about an essay that she wrote in school about how her mom was  
2203 her hero because not only did she fight against breast  
2204 cancer, she fought against the insurance company to try and  
2205 make things better for other people in the future.

2206 So my question, I guess, is, that was a decade ago, is  
2207 it better now? Are the treatments that the doctor is asking  
2208 for, are they covered? Dr. Brawley, would you like to  
2209 respond?

2210 Dr. {Brawley.} Yes, and I get in trouble for just  
2211 saying the flat-out truth. There have been instances where  
2212 the insurance companies have been wrong and there have been  
2213 instances where the patients have been wrong and there have

2214 been instances where physicians have been wrong. Ms. Visco  
2215 talked about bone marrow transplant for breast cancer. Very  
2216 quickly, the thumbnail history of that, in the early 1990s  
2217 many people thought high-dose chemotherapy with bone marrow  
2218 transplant would be beneficial for women at high risk for  
2219 relapse of breast cancer. Many hospitals started these bone  
2220 marrow transplant programs as a way of making money. Ten  
2221 State legislatures passed laws saying that insurance  
2222 companies had to pay for them. Many women sued their  
2223 insurance companies because they didn't want to pay for it.  
2224 There was no scientific evidence to support it. Ultimately,  
2225 this delayed the NCI studies that ultimately showed that bone  
2226 marrow transplant in breast cancer was more harmful than  
2227 helpful. This is when people stop being scientific and start  
2228 practicing--you know, earlier I said in my statement that one  
2229 of the problems with this disease is, it is a complex disease  
2230 and we all want to make it very simple and we all want to  
2231 have very simple messages. That is a darn good example of  
2232 how the simple message, more chemotherapy must be better,  
2233 actually killed women. It wasn't that it was just a waste of  
2234 money. It actually killed women.

2235 Ms. {Sutton.} I appreciate your answer, and I think  
2236 that again goes back to the point of, it isn't simple. It is  
2237 all very multi-faceted and there are unique considerations in

2238 every story right, so it is very difficult to--

2239 Dr. {Brawley.} But Congresswoman Sutton, the answer to  
2240 your question is what you described does happen where people  
2241 want to get the right therapy and someone in an insurance  
2242 company or others somehow decides that they should not get  
2243 the right therapy. That does happen.

2244 Ms. {Sutton.} It is one thing to make a determination  
2245 based on health needs and it is another thing to make a  
2246 determination based on money.

2247 Ms. {Luray.} And Congresswoman, if I may add, there is  
2248 the issue of access to experimental treatment and how that  
2249 access is granted and whether or not it is based on  
2250 scientific evidence but there is also access to ongoing  
2251 treatment that many of our patients experience. There was a  
2252 young woman here, Anna van Lear, who had to fight her insurer  
2253 after being diagnosed with breast cancer, had to fight to get  
2254 her MRI because of her age, and that occurs again and again,  
2255 so the experimental treatments are one issue but it is the  
2256 ongoing need for surveillance care, side effects, et cetera  
2257 and having to battle the insurer every day, and of course the  
2258 economic loss that they experience too because of the high  
2259 out-of-pocket expenses.

2260 Ms. {Sutton.} Thank you.

2261 Dr. Weiss?

2262 Dr. {Weiss.} The cost of negotiating with the insurance  
2263 companies throughout each clinical day has lengthened my day  
2264 by 2 hours and it has slowed down the urgent feeling a  
2265 patient--you know, her ability to get what she needs when she  
2266 needs it, and we have doubled our office staff just to get  
2267 enough people on the phones to get the authorizations for  
2268 tests or for treatment or see a new doctor or to get a second  
2269 opinion and maybe even a third opinion in a complex case. So  
2270 in terms of the cost of health care, I don't think that these  
2271 barriers are saving us money, I think that we need these laws  
2272 today to give the physicians the ability to deliver the  
2273 optimal care in terms of early detection, treatment and  
2274 surveillance of women beyond their initial treatment.

2275 Ms. {Sutton.} Thank you.

2276 Mr. {Pallone.} Thank you.

2277 The gentleman from Iowa, Mr. Braley.

2278 Mr. {Braley.} Thank you, Mr. Chairman.

2279 Dr. Brawley, I want to follow up with your observation  
2280 because you might find it interesting to note that I used the  
2281 exact example that you were describing in an earlier markup  
2282 we were having on health care in this same conference room,  
2283 and one of the things we can't ignore is sometimes the  
2284 political implications of important public policy decisions  
2285 we are making that involve academic research, scientific

2286 research, medical research and most importantly people.  
2287 Because the story I used was from a book by Shannon Brownley.  
2288 It was given to me by a family practice doctor,  
2289 ``Overtreatment'' and this exact scenario that you were  
2290 describing is mentioned at length in that book, and this very  
2291 conference room was filled with women who were getting high-  
2292 does chemotherapy with bone marrow transplants and the person  
2293 who developed that treatment methodology was sitting in these  
2294 witness chairs and turned with his back to members of  
2295 Congress and had all those women stand up and then said to  
2296 the members sitting in this hearing room, ``Fifty percent of  
2297 these women will be dead if you don't approve funding for  
2298 this treatment.'' So we are really talking about a high-  
2299 stakes poker game here, and I think what all of us want to  
2300 get to is a health care delivery system that is based upon  
2301 evidence-based decision making that makes sense for the  
2302 greatest portion of the population.

2303 I had the opportunity before I came to Congress to  
2304 represent a retired swimming coach who was diagnosed with  
2305 prostate cancer, and the treatment of choice that he decided  
2306 upon was not covered by Blue Cross/Blue Shield through an  
2307 employer-sponsored health care plan, and after a lot of  
2308 research and investigation, we determined that Blue  
2309 Cross/Blue Shield was also the administrator for Medicare in

2310 the State of Iowa and covered that form of treatment as non-  
2311 experimental. So when we are talking about making health  
2312 care available to women who have been diagnosed with breast  
2313 cancer, we all need to know the best evidence available and  
2314 we also need to eliminate these bizarre distinctions between  
2315 coverage options so that no woman who has been diagnosed with  
2316 breast cancer is faced with the difficult decision of  
2317 deciding how she is going to pay for treatment under one  
2318 program that she could get if she was old enough to be  
2319 covered under Medicare or something else.

2320         And so one of the things I would like to ask the panel  
2321 about is why this particular class of women, younger women  
2322 who do not fit traditional theories of who is most likely to  
2323 be diagnosed with breast cancer, why are they more vulnerable  
2324 than other segments of the population, if they are, and what  
2325 types of attitudes do they bring to their treatment that make  
2326 them more challenging as a group, if they are, than other  
2327 groups of women?

2328         Dr. {Brawley.} If I could start first, sir, and thank  
2329 you. I truly do believe that adequate health care reform  
2330 includes reforming how we consume health care. We have to  
2331 all learn to be more scientific and appreciate the science  
2332 and the evidence. One aspect of the EARLY bill which I think  
2333 is important is, it actually puts aside some money to address

2334 the very questions that you just addressed: what is  
2335 different about younger women, how can we help younger women  
2336 who have this disease. That is actually some of the most  
2337 important parts of the EARLY bill. The ACS had some  
2338 difficulty with the bill early on because some of the  
2339 messages that were in it were not messages that we thought we  
2340 could support. We wanted evidence-based good messages. Now  
2341 we have scientists and survivors in a committee coming up  
2342 with what the evidence-based messages should be, but one  
2343 thing this bill always had was research to look at the  
2344 quality of life needs of women with breast cancer, women who  
2345 have been diagnosed who are in their 20s, 30s and 40s. That  
2346 has always been a very good part of this bill.

2347 Mr. {Braley.} Yes?

2348 Ms. {Visco.} I would say that we don't know very much  
2349 about breast cancer in any age group. There are some data  
2350 that younger women are more likely to be diagnosed with  
2351 triple negative breast cancer, a specific type of breast  
2352 cancer, for which we have treatments for estrogen receptor-  
2353 positive breast cancer that work well. We have treatments  
2354 for HER2 overexpressing breast cancer that works well. For  
2355 triple negative, we don't yet have targeted therapies that  
2356 work well. So more research into looking at that type of  
2357 breast cancer, although there are a number of new

2358 possibilities in clinical trials now.

2359           There is also the issue of fertility. I was 39 when I  
2360 was diagnosed. I had chemotherapy. I did go into premature  
2361 menopause. I didn't have the opportunity to have more  
2362 children. There are side effects with treatment no matter  
2363 how old you are. That is a side effect of treatment for  
2364 younger women. It is something we need to do more research  
2365 on. But we just don't have the information. We just don't  
2366 know enough about breast cancer and certainly not enough  
2367 about breast cancer in younger women.

2368           Dr. {Sledge.} I can only add a little, but these women  
2369 are vulnerable in many ways. One is, as Fran has just  
2370 mentioned, they are biologically vulnerable. They tend to  
2371 have much more aggressive cancers than do older women,  
2372 cancers that grow rapidly, cancers that are more likely to  
2373 spread to other parts of the body at an earlier point in  
2374 time, cancers that are less targetable in terms of hormonal  
2375 therapy or HER2-targeted therapy, so they are biologically  
2376 vulnerable. They are economically vulnerable. These are  
2377 women who by and large are less likely to have insurance just  
2378 because they are at an earlier point in their life and they  
2379 are not as far along up the chain that would allow them to  
2380 have a good health care ability to cushion any blows.  
2381 Economically, they can't cushion the blows because they don't

2382 have any money in the bank. Socially, they are vulnerable  
2383 because they perhaps just started their family or just got  
2384 married. They have to worry about these fertility issues  
2385 that a woman who is 20 or 30 years older would not have to  
2386 worry about. So across the board, Congressman, they are far  
2387 more vulnerable than our older patients.

2388         Mr. {Bralley.} Are the criteria that the AJCC staging  
2389 manual is using for breast cancer adequate to try to  
2390 delineate any of these specific concerns that you have  
2391 mentioned here today or are they using broad groupings of  
2392 women that don't allow us to have the ability to drill down  
2393 and define criteria that would be more age-appropriate for  
2394 different segments of the population?

2395         Dr. {Brawley.} Sir, I can only give my opinion as a  
2396 physician who treats breast cancer patients. I think the  
2397 AJCC which does the staging manual has done a good job  
2398 although it actually being reevaluated right now as we speak.  
2399 I think one of the great problems we have in breast cancer  
2400 is, our definition of what cancer is actually comes from some  
2401 German pathologist in the 1840s, and we have not actually  
2402 brought the definition into a molecular or genetic age. We  
2403 are still using the same science, looking at it under a  
2404 microscope with a glass to say this is cancer that we used  
2405 160 years ago, and one of the challenges to us in science is

2406 to find a genetic way to look at a tissue and say that this  
2407 particular tissue in this woman's breast is going to behave  
2408 in this particular way over the next 20, 30, 40 years and  
2409 that is how we ought to treat it. This particular tissue is  
2410 going to be very aggressive so we need to treat it  
2411 aggressively. This other woman's breast cancer is going to  
2412 be less aggressive so we will treat it or maybe even watch it  
2413 and be less aggressive. We have not gotten there but that is  
2414 where hopefully the science is going to take us. That is  
2415 hopefully where the sequencing of the human genome is going  
2416 to take us, and maybe 20 years from now we will be talking  
2417 about those tests.

2418 Mr. {Braley.} Thank you.

2419 Dr. {Weiss.} I would just also add that in the care of  
2420 any woman who has been diagnosed with breast cancer who is  
2421 also a mother, one of her biggest concerns is, what does my  
2422 diagnosis mean for the women in my family, and that question  
2423 comes up all the time and so that is an area of research that  
2424 I know we are all involved in that deserves much better  
2425 answers because if you don't deal with that profound fear and  
2426 concern for her, you haven't really taken care of the whole  
2427 woman or her whole family.

2428 Mr. {Braley.} Thank you very much.

2429 Mr. {Pallone.} Thank you all. I know it has been a

2430 long day. We had a delay and had votes and all that, but I  
2431 thank you for bearing with us, and this was very enlightening  
2432 in terms of the whole issue. As I said earlier, this was a  
2433 legislation hearing so we are going to have to sift through  
2434 all this and figure out what is in the health care reform and  
2435 what isn't, but we do intend to try to move the bills that  
2436 were considered today. And let me just mention that members  
2437 can still submit written questions to you. They are supposed  
2438 to submit them within 10 days and then the clerk notifies  
2439 you, so we may ask you to respond in writing to some  
2440 additional questions. But thanks again, and without  
2441 objection, this meeting of the Subcommittee is adjourned.

2442           [Whereupon, at 4:00 p.m., the Subcommittee was  
2443 adjourned.]