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4 EXAMINING H.R. 1786, THE JAMES ZADROGA 9/11 HEALTH AND

5 COMPENSATION REAUTHORIZATION ACT

6 THURSDAY, JUNE 11, 2015

7 House of Representatives,

8 Subcommittee on Health

9 Committee on Energy and Commerce

10 Washington, D.C.

11 The subcommittee met, pursuant to call, at 10:17 a.m.,

12 in Room 2123 of the Rayburn House Office Building, Hon.

13 Joseph R. Pitts [Chairman of the Subcommittee] presiding.

14 Members present: Representatives Pitts, Guthrie,

15 Whitfield, Shimkus, Burgess, Lance, Griffith, Bilirakis,

16 Long, Elmers, Bucshon, Brooks, Collins, Upton (ex officio),

17 Green, Engel, Schakowsky, Castor, Sarbanes, Schrader,

18 Kennedy, Cardenas, and Pallone (ex officio).

19 Also present: Representatives King, Maloney, Nadler,
20 Donovan, and Clarke.

21 Staff present: Clay Alspach, Chief Counsel, Health;
22 Gary Andres, Staff Director; Leighton Brown, Press Assistant;
23 Karen Christian, General Counsel; Noelle Clemente, Press
24 Secretary; Paul Edattel, Professional Staff Member, Health;
25 Carly McWilliams, Professional Staff Member, Health; Katie
26 Noraria, Professional Staff Member, Health; Tim Pataki,
27 Professional Staff Member; Graham Pittman, Legislative Clerk;
28 Adrianna Simonelli, Legislative Associate, Health; Heidi
29 Stirrup, Health Policy Coordinator; Greg Watson, Staff
30 Assistant; Christine Brennan, Democratic Press Secretary;
31 Jeff Carroll, Democratic Staff Director; Waverly Gordon,
32 Democratic Professional Staff Member; Tiffany Guarascio,
33 Democratic Deputy Staff Director and Chief Health Advisor;
34 Ashley Jones, Democratic Director of Communications, Member
35 Services and Outreach; Tim Robinson, Democratic Chief
36 Counsel; and Samantha Satchell, Democratic Policy Analyst.

|
37 Mr. {Pitts.} Ladies and gentlemen, if you will, if you
38 will take your seats, we will begin. I would like to ask all
39 of our guests today to please take their seats. The
40 subcommittee will come to order. The chair will recognize
41 himself for an opening statement.

42 Today's Health Subcommittee hearing will examine the
43 World Trade Center (WTC) Health Program that was created in
44 the James Zadroga 9/11 Health and Compensation Act enacted in
45 2011. The Act allocated \$4.2 billion to create the Health
46 Program, which provides monitoring, testing, and treatment
47 for people who worked in response and recovery operations, as
48 well as for other survivors of the 9/11 attacks. The
49 authorization of the Health Program ends on September 30,
50 2015. Another part of the law, the September 11th Victim
51 Compensation Fund, is under the jurisdiction of the Judiciary
52 Committee. It will continue to accept applications until
53 October 3, 2016, over a year after the Health Program
54 authorization ends.

55 The WTC Health Program funds networks of specialized
56 medical programs, and these programs are designed to monitor
57 and treat those with 9/11-related conditions. For
58 responders, The World Trade Center Medical Monitoring and
59 Treatment Program; for survivors, the NYC Health and

60 Hospitals Corporation WTC Environmental Health Center; for
61 NYFD personnel, the Fire Department of New York Responder
62 Health Program; the National Program, the WTC Health Program
63 has a nationwide network of clinics with providers across the
64 country for responders and survivors who live outside the New
65 York City metropolitan area. These programs provide free
66 medical services by health care professionals who specialize
67 in 9/11-related conditions.

68 Our colleagues, Representatives Carolyn Maloney, Peter
69 King, and Jerrold Nadler, have jointly introduced
70 legislation, H.R. 1786, the James Zadroga 9/11 Health and
71 Compensation Reauthorization Act, which reauthorizes the Act.
72 This legislation has begun an important conversation that
73 will lead to a timely and fully offset reauthorization of the
74 Health Program.

75 Today's hearing will allow us to learn more about how
76 the program is working and whether changes are needed. We
77 will hear from the Director of the National Institute for
78 Occupational Safety and Health, who is responsible for
79 administering the program, as well as from the medical
80 director of the Robert Wood Johnson Medical School, and 2
81 first responders who are enrolled in the World Trade Center
82 Health Program.

83 [The prepared statement of Mr. Pitts follows:]

84 ***** COMMITTEE INSERT *****

|

85 [The bill follows:]

86 ***** INSERT A *****

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87 Mr. {Pitts.} I look forward to the testimony today.
88 And I would like to yield the balance of my time to the
89 gentleman from New Jersey, Representative Lance.

90 Mr. {Lance.} Thank you, Mr. Chairman. It is my honor
91 to welcome David Howley, a constituent of mine in New
92 Jersey's seventh congressional district, to the committee
93 this morning.

94 David, thank you for making the trip from New Jersey to
95 share your story, and advocate for those who cannot be with
96 us today. We look forward to your testimony.

97 I first met David several months ago when he came into
98 my office in Westfield, New Jersey, to discuss the bill
99 before us today. And this Reauthorization Act is, I think,
100 critically important. David has been a tremendous advocate
101 for the legislation because, as he will detail in his
102 testimony, he knows firsthand the importance of these
103 programs for him and his fellow first responders and
104 survivors.

105 David joined the New York Police Department in 1985, and
106 served in various departments over his 21-year tenure. He is
107 a third generation law enforcement official; following the
108 tradition of his father and grandfather. He was serving in
109 the NYPD Operations Division on September 11, 2001, and spent

110 the next several months in the dust and rubble of Ground
111 Zero.

112 I am proud to have David here with us today, and I am
113 proud to be a cosponsor of this critical legislation.

114 It is my hope, Mr. Chairman, that we can work in a
115 bipartisan fashion to move this legislation forward quickly,
116 and I look forward to voting for it not only here and in full
117 committee, but on the Floor of the House of Representatives.

118 Mr. Chairman, I yield back the balance of my time.

119 [The prepared statement of Mr. Lance follows:]

120 ***** COMMITTEE INSERT *****

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121 Mr. {Pitts.} The chair thanks the gentleman. And I
122 also would note that some of our colleagues from the New York
123 delegation who are not on the committee, but very concerned
124 of this issue and sponsors of the legislation, have requested
125 to sit on the dais, and we welcome them this morning.

126 At this point, the chair recognizes the ranking member
127 of the subcommittee, Mr. Green, 5 minutes for an opening
128 statement.

129 Mr. {Green.} Thank you, Mr. Chairman, for holding the
130 hearing on this important program. I thank the witnesses
131 today, and for the first responders in the audience who--for
132 their bravery and service both on and after the tragic day of
133 9/11. Thank you for coming today to share your personal
134 experiences. The committee--and shed light on the
135 significance of the World Trade Center Health Programs.

136 No one here can forget the horrific attacks perpetrated
137 upon our country at the World Trade Center in New York, the
138 Pentagon, and Washington, and at the field in Shanksville,
139 Pennsylvania. During and after the attacks, tens of
140 thousands of first responders, including police,
141 firefighters, emergency medical workers, jumped into action
142 to assist in rescue, recovery, and cleanup. As a result of
143 their service, these responders were exposed to dust, smoke,

144 toxins, such as pulverized concrete, fibrosis, glass,
145 particulate matter, and asbestos. This exposure caused many
146 of them to develop a spectrum of debilitating diseases,
147 including respiratory disorders like asthma, skin, prostate,
148 and lymphedema cancers. A GAO report on the 9/11 Health
149 Program suggested that firefighters who responded to the
150 attack ``experienced a decline in lung function equivalent to
151 that of which produced by 12 years of aging.''

152 In addition to the physical ailments these heroes now
153 have, many have suffered post-traumatic stress syndrome,
154 PTSD, depression, anxiety stemming from psychological trauma
155 they experienced in the aftermath of the attack.

156 Nearly 1 decade after the September 11 terrorist
157 attacks, the James Zadroga 911/ Health and Compensation Act
158 was signed into law in 2010. The Zadroga Act created the
159 World Trade Center Health Program within the Department of
160 Health and Human Services. The program provided evaluation,
161 monitoring, and medical necessary physical and mental health
162 treatments to first responders and certified eligible
163 survivors of the World Trade Center-related illnesses. It
164 has also established a network of clinical Centers of
165 Excellence and data centers. For these responders and
166 survivors who reside outside the New York area, the Act
167 created a national network of health providers who provide

168 the same types of services for World Trade Center-related
169 illnesses. While cancer was not originally listed among the
170 statutory WTC-related health conditions, 60 types of cancer
171 were added in 2012, after a petition by Members of Congress.
172 As of May the 5th of this year, 37,000 members of the health
173 program had cancer.

174 The Act also established the Victims Compensation Fund
175 that provides compensation for harm suffered as a result of
176 debris removal. Without action by Congress, funding for the
177 current Health Program will terminate on September of 2016.

178 The James Zadroga 9/11 Health and Compensation
179 Reauthorization will reauthorize the critical World Trade
180 Center Health Program and the Victims Compensation Fund.

181 As requires under the current program, New York City
182 will continue to pay 10 percent of the total cost. It is
183 important to note that WTC Health Program serves our heroes
184 nationwide, and extends far beyond the New York area. Both
185 these and currently enrolled and future enrollees live in all
186 areas of the country. In fact, as of August 2014, 429 of the
187 435 congressional districts were home to at least 1 9/11
188 responder or survivor.

189 We must not abandon those who bravely sacrificed their
190 own wellbeing on behalf of the country in the wake of
191 terrible attacks. If--we have a duty to serve our first

192 responders and survivors and heroes with complex healthcare
193 from 9/11. It is critically important that we support the
194 James Zadroga 9/11 Health Compensation Reauthorization Act.

195 I would like to thank the first responders for their
196 gallant and selfless service on and after 9/11. I would also
197 like to thank the doctors and administrators of the program
198 for their efforts to treat the complex illnesses afflicted on
199 our first responders, and continued research on the impact of
200 exposure to toxins and psychological trauma.

201 Mr. Chairman, I--if someone on our side of the aisle
202 would like a minute, I would be glad to yield to them. I
203 would like to yield to my college from New York.

204 [The prepared statement of Mr. Green follows:]

205 ***** COMMITTEE INSERT *****

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206 Ms. {Clarke.} I thank the ranking member of the
207 subcommittee, as well as the chairman. And welcome our
208 witnesses here today.

209 While not a member of this subcommittee, I am a member
210 of the full Committee on Energy and Commerce. I am
211 Congresswoman Clarke of New York. And I wanted to thank
212 Chairman Pitts and Ranking Member Green for holding this
213 hearing, and allowing me to sit in this very important
214 hearing. Also want to thank our panelists. It is a--good
215 that you have shared your experiences and remind America of
216 the importance of renewing this very important program. This
217 is a great first step toward reauthorization, in a time when
218 the American people are skeptical about the work of Congress,
219 so I am happy that this committee is working in a bipartisan
220 fashion to move expeditiously to renew this important
221 health--these important health programs. Congress must move
222 forward to ensure first responders and survivors of the 9/11
223 terrorist attacks on the World Trade Center, the Pentagon,
224 and Shanksville, Pennsylvania, continue to receive the care
225 they deserve and they so sorely need.

226 With that, Mr. Chairman, Mr. Ranking Member, I yield
227 back the time.

228 [The prepared statement of Ms. Clarke follows:]

229 ***** COMMITTEE INSERT *****

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230 Mr. {Green.} Mr. Chairman, I yield back.

231 Mr. {Pitts.} The chair thanks the gentleman.

232 Now recognize the chair of the full committee,
233 gentleman--Mr. Upton, 5 minutes for an opening statement.

234 The {Chairman.} Well, thank you, Mr. Chairman.

235 Now, back on September 11, '01, the world as we knew it
236 was turned upside down by unthinkable acts of terrorism,
237 which took the lives of nearly 3,000 individuals in New York,
238 Pennsylvania, and Virginia, left a mark on every American.
239 Every one of us was impacted. From the smoldering ruins of
240 the Twin Towers and the Pentagon to the wreckage of United
241 Airlines Flight 93, the painful images and heartbreaking
242 personal stories of that day, every minute, will not be
243 forgotten.

244 We remember the thousands of innocent lives lost and the
245 communities of loved ones they left behind, and many of us
246 met with those. We also honor the countless acts of heroism
247 and leadership shown by brave American men and women in those
248 hours of pandemonium and in the days, weeks, months, and now
249 years that have followed. Then, for me, as Chair of the
250 Telecom Subcommittee on this committee, I led a bipartisan
251 delegation, both to New York and to the Pentagon, where we
252 witnessed firsthand the valiant efforts of our first

253 responders who were certainly exhausted, overwhelmed, but
254 still working 21--24/7. First responders spent hours, days
255 in air that was thick with dust and smoke, digging through
256 the rubble, searching for survivors.

257 When I visited Ground Zero, New York's finest were still
258 working round the clock in impossible conditions for the
259 recovery efforts. Their selfless work took a toll on their
260 health. We know that. The Federal Government provided aid
261 to those individuals who were injured and the families of
262 those who were killed in the attacks through a discretionary
263 grant program, as we should.

264 In 2011, the Zadroga 9/11 Health and Compensation Act
265 established the World Trade Center Health Program and the
266 Victim Compensation Fund. Our Ranking Member, Frank Pallone,
267 and our New York colleagues Representative Carolyn Maloney,
268 Peter King, Jerry Nadler, have jointly introduced now H.R.
269 1786, the James Zadroga 9/11 Health and Compensation
270 Reauthorization Act, which would reauthorize both of these
271 programs.

272 At today's hearing, we are going to focus on the World
273 Trade Center Health Program as it is the program that falls
274 in this committee's jurisdiction. The authorization for the
275 World Trade Center Health Program ends at the end of
276 September, just a few months from now, while the Victim

277 Compensation Fund remains open to applicants into October of
278 2016.

279 The WTC Health Program funds networks of specialized
280 medical programs designed to monitor and treat those with
281 9/11-related conditions. The members enrolled in the program
282 are not just from the greater New York area. In 2014, there
283 were 71,942 individuals in the World Trade Center Health
284 Program from 429 of the 435 congressional districts. In
285 fact, there are 75 Michigan residents currently enrolled in
286 the WTC Health Program. Today's hearing is, yes, an
287 important opportunity to learn more about how the World Trade
288 Center Health Program has operated since its authorization
289 in, and what is needed for it to successfully operate and
290 meet the needs of its members in the future.

291 I want to thank all of the witnesses today for taking
292 the time to be here, especially thank Officer Howley and
293 Detective Burnette for their service to our great country,
294 and for sharing their personal stories and struggles with
295 this subcommittee. The bill needs to be passed, and I will
296 look to consider every effort to make sure that we get it to
297 the House Floor prior to its--prior to the end of September
298 so that we will have an opportunity to make sure that these
299 victims are taken care of.

300 And I yield back the balance of my time.

301 [The prepared statement of Mr. Upton follows:]

302 ***** COMMITTEE INSERT *****

|
303 Mr. {Pitts.} The chair thanks the gentleman.

304 And now the chair is pleased to recognize the ranking
305 member of the full committee, gentleman who has many
306 constituents impacted by this issue, Mr. Pallone, 5 minutes
307 for an opening statement.

308 Mr. {Pallone.} Thank you, Chairman Pitts, and also
309 Chairman Upton. And I particularly want to thank Chairman
310 Upton for the comments he just made, you know, highlighting
311 how we need to perceive this as a national program, and
312 impacting people who came and helped out on 9/11 and the
313 aftermath from all parts of the country.

314 My staff probably is tired of my telling this story, but
315 I remember within a few days after the attack, we went up to
316 New York City with President Bush, and I was standing next to
317 this big yellow fire engine that said Hialeah, Florida. And
318 I said, what is this truck doing from Hialeah, because I
319 think it was only 1 or 2 days after, and I wondered how it
320 even got there so quickly. And I talked to the firemen from
321 Hialeah, Florida, and they said, oh, we just--as soon as this
322 happened, we just got in our fire truck and we drove up from
323 Florida because we wanted to help. And it just struck me at
324 the time about how so many people responded from all over the
325 country, and so many people were injured because of the fact

326 that they were there for a few days or a few weeks or a few
327 months even.

328 So this bill is a critical first step in ensuring that
329 the 9/11 Health Program is extended as soon as possible. As
330 you both already know, this is one of my top priorities for
331 2015, and I am grateful for Chairman Pitts and Upton for your
332 willingness to work with us to ensure the timely passage of
333 this bill.

334 I have to recognize all the first responders who are
335 here, and to whom we owe a depth of gratitude. I also want
336 to acknowledge Dr. Iris Udasin who runs the New Jersey 9/11
337 Health Clinic. Thank you for being here to share your
338 expertise and experience with us today. And let me also
339 mention all the New Yorkers, Representative Maloney, the
340 sponsor of the bill. I don't know if Representative Nadler
341 is here, but certainly he has been involved from the
342 beginning. Representative King I see, who joined the
343 committee today, as well as our representatives, Yvette
344 Clarke, Eliot Engel, and also my colleague from New Jersey,
345 Leonard Lance, who is the cosponsor. Since day 1, you have
346 all fought tirelessly to ensure that our Nation's 9/11
347 responders and survivors are cared for, and I am proud to
348 fight alongside you.

349 Beyond the immediate loss of life of 9/11, we now know

350 with great documentation that thousands of first responders
351 and survivors of the attacks are now suffering debilitating
352 illnesses from its aftermath, and in fact, more than 100
353 firefighters and 50 law enforcement officers have reportedly
354 lost their lives to WTC-related health conditions.

355 Additionally, more than 1,500 active duty firefighters and
356 EMS personnel, and over 550 law enforcement officers were
357 forced to retire due to WTC-related health conditions.

358 We now have a deep understanding of how the tons of
359 dust, glass fragments, and other toxins released into the air
360 affected both responders and survivors. Illnesses include
361 respiratory diseases, gastroesophageal disorders, mental
362 health conditions, and cancer. And that is why the James
363 Zadroga 9/11 Health and Compensation Act, signed into law in
364 2011, is so critical. It established a program to monitor
365 and screen eligible responders and survivors, and provides
366 medical treatment to those who are suffering from World Trade
367 Center-related diseases. But what is so important to note is
368 that this program isn't there to provide health insurance.
369 These are complicated conditions that are chronic in nature,
370 and require special expertise to appropriately diagnose and
371 treat. That is why the program includes a network of clinics
372 and providers specifically trained to treat these diseases.
373 It also ensures that providers and survivors bear no out-of-

374 pocket costs associated with these particular health
375 conditions.

376 The WTC Health Program currently provides monitoring and
377 treatment services for more than 71,000 responders and
378 survivors. They reside in every state, and in 429 of the 435
379 congressional districts. If some of you don't know, the law
380 is named for James Zadroga, a New Jersey hero who responded
381 on 9/11, and spent hundreds of hours digging through World
382 Trade Center debris. Mr. Zadroga died in 2006 from pulmonary
383 disease and respiratory failure after his exposure to toxic
384 dust at the World Trade Center site. Like him, thousands of
385 people from all over this country came to the aid of our
386 country, and helped others at Ground Zero. Those responders
387 and survivors should not be abandoned, and I hope we can
388 extend the health program without delay.

389 I just--I only have 30 seconds left for Mr. Engel, I
390 apologize, but I yield to him.

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

392 ***** COMMITTEE INSERT *****

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393 Mr. {Engel.} Well, thank you. I thank the gentleman
394 for yielding. And let me agree with everything you said.

395 In the aftermath of September 11, it is estimated that
396 up to 400,000 Americans were exposed to copious amounts of
397 smoke and toxic substances, such as asbestos, and as a
398 result, many of our heroes now suffer from these debilitating
399 conditions; acute respiratory disorders, cancer, depression,
400 post-traumatic stress disorder, and it goes on and on. And
401 it is heartbreaking that the 9/11 survivors and first
402 responders who have already given so much must now carry the
403 burdens of these lung ailments, brain, very least we can do
404 in thanks is to help them.

405 So I was proud to be an original cosponsor of the James
406 Zadroga 9/11 Health and Compensation Act, and I am proud to
407 be an original cosponsor of the reauthorization we are
408 discussing today. A failure on Congress' part to pass this
409 vital legislation would constitute an egregious affront to
410 the Americans who gave so much on 9/11 in service to their
411 country. And I specifically say Americans because the
412 population of those who will benefit from this
413 reauthorization spans the entire United States. It is 429 of
414 the 435 congressional districts that benefit from these
415 programs. So this is an issue of national performance. So

416 the first responders who rely on the World Trade Center
417 Health Program did not hesitate to risk their lives for
418 fellow Americans on 9/11, and we should not hesitate to care
419 for them now. So it is of critical importance that we
420 permanently reauthorize the James Zadroga 9/11 Health and
421 Compensation Act.

422 Thank you, Mr. Pallone. Thank you, Mr. Chairman.

423 [The prepared statement of Mr. Engel follows:]

424 ***** COMMITTEE INSERT *****

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425 Mr. {Pitts.} The chair thanks the gentleman.

426 And as usual, all members' opening statements--written
427 opening statements will be made part of the record.

428 That concludes our time for opening statement. I have a
429 unanimous consent request. I would like to submit the
430 following documents for the record. Statements from
431 Representative Peter King, New York, 2nd District. From the
432 International Association of Firefighters, from the Sergeants
433 Benevolent Association, from the National Association of
434 Police Organizations, and an article from the New York City's
435 Patrolman's Benevolent Association featuring Mr. David
436 Howley.

437 Without objection, so ordered.

438 [The information follows:]

439 ***** COMMITTEE INSERT *****

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440 Mr. {Pitts.} We have 2 panels today. On our first
441 panel we have Dr. John Howard, Director, National Institute
442 for Occupational Safety and Health. Thank you very much for
443 coming today, Dr. Howard. Your written statement will be
444 made part of the record. You will be recognized for 5
445 minutes to make your opening statement. At this time, you
446 are recognized. Welcome.

|
447 ^STATEMENT OF DR. JOHN HOWARD, DIRECTOR, NATIONAL INSTITUTE
448 FOR OCCUPATIONAL SAFETY AND HEALTH (NIOSH)

449 } Dr. {Howard.} Thank you, Mr. Chairman, and
450 distinguished members of the committee. My name is John
451 Howard, and I am the administrator of the World Trade Center
452 Health Program. I am very pleased to appear before you today
453 to discuss the program and those it serves, who responded to
454 or survived the September 11, 2001, terrorist attacks on New
455 York City, and those who responded at the Pentagon and in
456 Shanksville, Pennsylvania.

457 The program's members responded to an epic disaster, and
458 as a result, suffer mental and physical injury, illness, and
459 the risk of premature death. The program's members responded
460 to the 9/11 disaster from all 50 states, and as has been
461 stated, from 429 of the 435 congressional districts. The
462 original effort to care for those affected by 9/11 toxic
463 exposures operated as a series of cooperative agreements and
464 grants. As a discretionarily funded program, it depended on
465 year-to-year appropriations, making it challenging to plan
466 adequately to--for the members' ongoing health needs. In
467 January 2011, as has been stated, the James Zadroga 9/11
468 Health and Compensation Act became law. Stabilization of

469 funding allows the program to more adequately care for 9/11
470 responders. In calendar year 2014, of the 71,942 current
471 members enrolled in the program, 20,883 members received
472 treatment for health conditions arising from hazardous
473 exposures from 9/11, and 28,059 members received health
474 monitoring to ensure early medical intervention for any
475 developing health condition that is specified for coverage by
476 the program.

477 Since the program's implementation, members have been
478 treated for a number of different health conditions. For
479 example, 11,473 members have been treated for asthma, 6,672
480 members have been treated for post-traumatic stress disorder,
481 and 6,497 members have been treated for chronic respiratory
482 disorders. The majority of our members suffer from multiple
483 mental and physical health conditions, and take multiple
484 medications for these conditions. Certain types of cancer
485 were added to the list of health conditions covered by the
486 program in late 2012. Since then, the program has certified
487 4,265 cases of cancer.

488 The World Trade Center Health Program fills a unique
489 need in the lives of our members and for our society. First,
490 members are evaluated and treated by medical providers who
491 have a depth of experience dating back to September 11, 2001,
492 and the physical and mental health needs of 9/11 responders

493 and survivors they are very familiar with. Their extensive
494 clinical experience with the responder and survivor
495 populations, as well as their understanding of the role of
496 exposure in causing disease, exceeds the training of
497 providers unfamiliar with the types of exposures and health
498 conditions common to the 9/11 population, and how to make the
499 connection between exposure and illness that the Zadroga Act
500 requires.

501 Second, our members are receiving health care that
502 cannot be provided, or only provided with great difficulty by
503 other types of insurance plans. For example, health
504 insurance plans do not routinely cover work-related health
505 conditions, leaving such coverage to Workers' Compensation
506 insurance. However, Workers' Compensation insurance often
507 presents coverage challenges to members because their 9/11
508 health conditions often first manifest after 9/11, many years
509 later, beyond the statute of limitations found in most state
510 Workers' Compensation laws. The World Trade Center Health
511 Program serves a vital role in overcoming the difficulties
512 that members might otherwise experience in its absence.
513 Without the program, 9/11 responders and survivors might end
514 up in limbo instead of in treatment.

515 Third, by providing evaluation and treatment for those
516 most affected by 9/11 as a unified cohort, the program

517 greatly aids not only the individual members, but also our
518 national understanding of the long-term health effects of
519 9/11, including its effects on children. The program helps
520 us better prepare for the medical needs arising from large-
521 scale, long duration disasters that might not, hopefully,
522 occur ever in the future.

523 Thank you for the opportunity to testify, and I am happy
524 to answer any questions you may have.

525 [The prepared statement of Dr. Howard follows:]

526 ***** INSERT 1 *****

|
527 Mr. {Pitts.} The chair thanks the gentleman. And I
528 will begin the questioning and recognize myself 5 minutes for
529 that purpose.

530 Dr. Howard, would you continue to elaborate a little bit
531 on the history of the World Trade Center Health Program, how
532 it came to be, how it has changed over time?

533 Dr. {Howard.} Thank you. The program started as a--an
534 immediate response to what doctors were seeing, especially
535 with the New York City Fire Department, in what was called at
536 that time a World Trade Center cough, and those doctors and
537 others that were recruited to the effort began to observe
538 that individuals who were responding were becoming ill from
539 inhalation of the dust and the toxins contained in the dust.
540 So immediately, through FEMA appropriations, CDC and then the
541 National Institute for Occupational Safety and Health, was
542 able to offer grants and cooperative agreements so that those
543 doctors could begin now many, many years later, their first
544 work in trying to articulate, characterize the issues that
545 responders were facing, and survivors.

546 Mr. {Pitts.} Another question. What are the
547 consequences of letting the World Trade Center Health Program
548 expire in September of 2015? How would it affect the
549 operation of the Centers of Excellence across the country,

550 and the patients who use these facilities and services?

551 Dr. {Howard.} Certainly, any of us that receive health
552 care from a particular health plan, if we are notified that
553 that plan no longer exists, creates great stress in our life.
554 We have to adjust to new providers and other changes. Our
555 efforts to help those who may be a part of our discontinued
556 program, let's hope that does not happen, would have to
557 receive other providers of care, and it would be our
558 responsibility to make sure they did.

559 The Centers of Excellence would not operate anymore as a
560 coordinated care operation for responders and survivors.

561 Mr. {Pitts.} Thank you. Now, we are aware that Special
562 Master Sheila Birnbaum administers the Victim Compensation
563 Fund, which is housed at the Department of Justice. Is there
564 coordination between the operations of the Victims
565 Compensation Fund and the World Trade Center Health Program?

566 Dr. {Howard.} Yes, sir, there is. We have data sharing
567 and medical review agreements with the Victims Compensation
568 Fund. We regularly meet with the staff. Our staff is
569 embedded with their staff to assist in the medical review.
570 The Victims Compensation Fund has adopted our program
571 requirements for their medical review. To date, we have
572 provided information to them on 18,262 of their VCF
573 claimants. We continue to work very closely with the Victims

574 Compensation Fund.

575 Mr. {Pitts.} How much higher is the Federal Employees
576 Compensation Act, FECA, compensation rate compared to
577 Medicare Parts A and B reimbursements for hospitals?

578 Dr. {Howard.} The statute--the Zadroga Act sets the
579 reimbursement rate according to the Workers' Compensation
580 rates of the Federal Government, the FECA rates. Medicare
581 rates are lower, but maybe by 10 to 20 percent lower. So
582 they are a--the FECA rates are higher and our reimbursement
583 rates for providers are higher than Medicare.

584 Mr. {Pitts.} Dr. Howard, I can imagine that it is a
585 logistical challenge to provide care for the responders and
586 survivors who are scattered all across the country. What can
587 you do to ensure that a physician in another part of the
588 country, seeing only a few World Trade Center patients,
589 benefits from the clinical experience of the physicians in
590 the New York metropolitan region who have more experience
591 treating these WTC-related health conditions?

592 Dr. {Howard.} The Nationwide Provider Network that we
593 have, which is currently seeing about 8,287 individuals, we
594 have total coordination with that provider network. On the
595 one hand, all of those individuals who do monitoring for our
596 survivors and responders that are in the nationwide program
597 are trained--occupationally trained physicians so that they

598 are equivalent to the physicians that we have in our Centers
599 of Excellence in New York and New Jersey. We also provide
600 them with additional training. We are working with Medscape
601 right now to have online training available for all of our
602 providers. We work with the--our contractor, LHI, which has
603 the Nationwide Provider Network, and that physician, their
604 medical director, sits in all of our groups and committees,
605 and we engage actively with those physicians. So I would say
606 that for our relationship with the national--the Nationwide
607 Provider Network, those physicians are on par with our
608 physicians at the CCEs.

609 Mr. {Pitts.} Good. Thank you very much. My time has
610 expired.

611 The chair now recognizes the ranking member of the
612 subcommittee, Mr. Green, 5 minutes for questions.

613 Mr. {Green.} Dr. Howard, prior to the passage of the
614 James Zadroga 9/11 Health and Compensation Act of 2010, you
615 administered the CDC grant program that funded medical
616 monitoring and treatment services for 9/11 survivors and
617 responders. That program was funded through discretionary
618 dollars, and there is always uncertainty about whether and
619 what amount of discretionary funding would be appropriated
620 for the grant program.

621 Dr. Howard, can you describe how the creation of the

622 World Trade Center Health Program, through the Zadroga Act,
623 has improved your ability to ensure that responders and
624 survivors get the quality medical services that they need?

625 Dr. {Howard.} Thank you. I would respond in 2 ways.
626 One, on behalf of the members, it is very stressful to
627 constantly be told on a year-by-year basis that your care may
628 go away, your doctor and the institution, the facility that
629 you go to, may change. So it created a pervasive sense of
630 stress. Mind you, in our population, we have many thousands
631 of individuals that suffer from PTSD, and some highly
632 resistant PTSD, and I am sure that if they were here with me,
633 they would say how stressful year-by-year funding is to the
634 program.

635 From the administrative perspective, it is very
636 difficult because we were always up to the last minute,
637 thinking should we start preparing for the program not to be
638 funded, and that was certainly something that we did not want
639 to happen, but it requires a long process of preparation. So
640 we were never sure about that.

641 Mr. {Green.} So the dedicated mandatory fundings helped
642 you not only plan better, but also the reaction from the
643 patients.

644 Dr. {Howard.} It is like night and day. When the
645 Zadroga Act passed, I think all of us, members and us that

646 were administrating the program, breathed a sigh of relief
647 that we had 5 years. We never had that before.

648 Mr. {Green.} Okay. The James Zadroga 9/11 Health and
649 Compensation Reauthorization would permanently extend the
650 program. Could you explain how a permanent extension of the
651 program would ensure that responders and survivors have that
652 peace of mind? You talked about that medical monitoring and
653 treatments it is--they come to rely on will continue to meet
654 their needs.

655 Dr. {Howard.} Well, as I say, I think that the
656 assurance of having the same provider, especially for our
657 patients that suffer from very serious mental and physical
658 conditions, is a peace of mind that can only be bought from
659 mandatory funding without a--an end date. For us in the
660 program, it really helps us do long-term strategic planning.
661 It is very hard to do contracts when you can only provide a
662 year or 2, or 5 years, but being able to look beyond that
663 5-year horizon is extremely helpful for the efficiency and
664 the integrity of the program.

665 Mr. {Green.} It seems the patients enjoy a great deal
666 of understanding from the providers--the doctors and
667 providers in the program. How do you think this affects the
668 patient outcomes?

669 Dr. {Howard.} Without doubt, the providers that I first

670 met in August of 2002, when I became first involved in this
671 program, are the very same providers that I see now in June
672 of 2015. Their dedication to this population has been worthy
673 of note.

674 Mr. {Green.} So the doctor-patient relation is
675 important because of the continuation of the program.

676 Dr. {Howard.} The trust that our members have to the
677 providers that we are fortunate to have cannot be duplicated
678 anywhere else.

679 Mr. {Green.} Do you think continuing the program is so
680 important it--to ensuring the same level of knowledge and
681 expertise?

682 Dr. {Howard.} Very definitely. Our providers have a
683 wealth of clinical information that other providers would
684 take them years to develop.

685 Mr. {Green.} Okay. Thank you, Mr. Chairman. I yield
686 back my time.

687 Mr. {Pitts.} The chair thanks the gentleman.

688 Now recognize the vice chairman of the subcommittee,
689 gentleman from Kentucky, Mr. Guthrie, 5 minutes for
690 questions.

691 Mr. {Guthrie.} Thank you, Mr. Chairman. Thank you, Dr.
692 Howard, for being here.

693 And I spent, I guess, 6 years of my life in college and

694 grad school in metro New York, and one of my favorite things
695 to do back when I was an undergrad is use the USO, and spent
696 a lot of time at the USO off Times Square. There was always
697 uniformed public servants there, and it was always enjoyed
698 getting to know and talk to them. I am a talker, so I
699 engaged with them, and what a great service that people feel.

700 You had--actually I wasn't going to go this direction,
701 but I think it is important to talk about, and it has opened
702 my eyes a little bit in what you said. I will kind of
703 emphasize or maybe go a little bit further. You know, I live
704 in Bowling Green, Kentucky, so where we take care of our
705 servants as well as--if a fire--if there is a fire, someone
706 goes into the firehouse and they get injured or whatever, you
707 know, we have assistance in place to--disability, insurance
708 and so forth. And so I think a lot of us that aren't, you
709 know, in New York continuously and the surrounding areas,
710 like some of my friends here, is that, you know, are the
711 programs already in place, and so what you have hit on today
712 is probably the first time I have thought of it. I know it
713 is unique in the massiveness of it, but why is it unique in
714 terms of other injuries that people might receive in other--
715 that requires its own system, other than just the volume.
716 But--so could you hit the challenges, because that--because
717 you have opened my eyes to some things today, and hit the

718 challenges that--you have already kind of said, but emphasize
719 why this is completely unique, that needs its own program,
720 why diseases are different than if you were in a normal or
721 a--well, I don't know if normal is the right word, but a more
722 standard, I guess, kind of situation that firefighters or
723 other people would be in?

724 Dr. {Howard.} I would be happy to. And I think the
725 best way to answer that question is by looking at some of the
726 findings that we have gotten from the investment that the Act
727 has allowed us to make in research, looking at this
728 population and the conditions. And I will just mention a few
729 issues. On the mental health issue, we have seen a delayed
730 onset of PTSD. Now, that is not normally seen in other types
731 of situations. That is something that we are seeing in this
732 population. It is--we have also seen a worsening of PTSD
733 despite conventional treatments. So that is something that
734 is new in this population. In terms of respiratory disease,
735 we are seeing an onset of obstructive airways disease beyond
736 5 years after exposure. We are also seeing bronchial hyper-
737 reactivity persist over a decade, and that is something new.
738 In terms of asthma, we have seen patients in our program who
739 have asthma, who have lost full-time employment because of
740 their asthma, more than we have seen in the general asthmatic
741 population.

742 So there are a number of findings that we are seeing
743 from a clinical perspective in this population that we would
744 never have learned had we not had the group together.

745 Mr. {Guthrie.} If it was just normal Workers' Comp. or
746 other things. And so I want to get to another thing. So you
747 said there are 71,000 people in the program. How do you--
748 what is the criteria--do you have--did you have to be on-site
749 for so many days, or I mean--

750 Dr. {Howard.} Well--

751 Mr. {Guthrie.} --or did you have to actually be in the
752 rubble, or are you--

753 Dr. {Howard.} The simple answer--

754 Mr. {Guthrie.} --blocks away, I mean what is the--

755 Dr. {Howard.} The simple answer is that the Zadroga Act
756 is highly specific about the criteria for eligibility in the
757 program. And it includes for--let's say for New York City
758 police officers, location, the duration of their exposure,
759 and other factors. So eligibility criteria are pretty well
760 spelled out in the Act.

761 Mr. {Guthrie.} What about the non-public safety
762 personnel that can be in the program?

763 Dr. {Howard.} Right. There are criteria for
764 eligibility for volunteers that came from all over the
765 country to volunteer as responders. Similarly, in the

766 section of the Act that has to do with survivors, there are
767 eligibility--5 levels of eligibility requirements for
768 survivors. So if someone comes to our program, wants to be a
769 member, the first step is filling out an application in which
770 they--a lengthy application, unfortunately, I might add, in
771 which all of that information is solicited so that we can
772 establish whether or not their experience meets the
773 eligibility requirements of the Act.

774 Mr. {Guthrie.} And I think some concerns, as we debated
775 before, I just want to emphasize this, is that anywhere in
776 terms of health care and people getting the care whatever
777 they deserve, I think--I know I remember asking the question,
778 why such a separate, unique program, and you have given me
779 some really good things to think about, so I really
780 appreciate it very much.

781 Appreciate it and I yield back.

782 Dr. {Howard.} Thank you.

783 Mr. {Pitts.} The chair thanks the gentleman.

784 And now recognize the ranking member of the full
785 committee, Mr. Pallone, 5 minutes for questions.

786 Mr. {Pallone.} Thank you, Mr. Chairman.

787 Dr. Howard, the World Trade Center Health Program relies
788 on clinical Centers of Excellence to provide most of the
789 monitoring and medical care through the program, and those

790 centers employ clinicians that have both the specialized
791 knowledge base and deep experience in treating the unique
792 physical and mental health needs of 9/11 responders. And I
793 know you have already talked about this, I am kind of
794 following up on what Mr. Guthrie said. I know that patients
795 in the New York City metropolitan region continue to see
796 their personal physicians for their general health care
797 needs, but often obtain monitoring and treatment services for
798 their conditions at these centers. And I also understand
799 that, you know, if somebody is in another part of the country
800 they can go to a network of doctors that are provided through
801 the program. But some of them also come to the centers. I
802 know that at the New Jersey centers we get people from all
803 over the country that will travel just because of the
804 expertise that exists.

805 So if you could just comment on the treatment benefits
806 of individuals using these centers rather than their personal
807 physicians for their 9/11-related health conditions, or even,
808 you know, traveling when they can see someone who is part of
809 the WTC network, they could come to the centers.

810 Dr. {Howard.} Yes, I would be happy to. And I think it
811 boils down to the difference in physicians in terms of their
812 expertise, as you said. Occupational and environmental
813 physicians who are schooled in that particular subspecialty

814 know how to connect an exposure with a health condition.
815 When I went to medical school, I did not learn that. I
816 learned how to take care of a health condition; I didn't
817 learn to go back and do an extensive history to try to figure
818 out what were your exposures, and was that exposure related
819 to this health condition that I see. That is a specialty of
820 occupational and environmental medicine where we try to
821 correlate the exposure and the health condition.

822 So physicians that are--that we use both in the CCEs
823 that are--have been involved since 2001, and in the
824 Nationwide Provider Network, have that capability.
825 Physicians that don't have that capability would not be able
826 to listen to the patient's symptoms and be able to say, yes,
827 your exposure--I am going to make a determination that your
828 exposure caused that health condition, or contributed to that
829 health condition, or aggravated that health condition.

830 Mr. {Pallone.} All right. I am trying to speed up here
831 because I wanted to ask you--

832 Dr. {Howard.} Right.

833 Mr. {Pallone.} --a few more things. Have there been
834 any problems with misdiagnosis or improper treatment of 9/11-
835 related health conditions when individuals have relied on
836 their personal physicians?

837 Dr. {Howard.} Not that I am aware of.

838 Mr. {Pallone.} Okay.

839 Dr. {Howard.} Within the program, of course, we have a
840 quality assurance where we look at all of the care that is--

841 Mr. {Pallone.} Okay. And can you just discuss briefly
842 how the clinical Centers of Excellence coordinate the care
843 delivered to responders and survivors at the centers, with
844 care delivered by their personal medical providers outside
845 the centers, briefly?

846 Dr. {Howard.} Sure. As many of you know, the World
847 Trade Center Health Program is a hybrid program. It is not
848 your normal health plan where you go in and everything that
849 you may complain about relative to your body, a physician
850 takes care of. We have a limited number of conditions. So
851 many conditions we don't cover, so you have to see an
852 additional physician, your personal physician. So that
853 coordination is done in the CCEs so that if those CCE
854 physicians see a condition that we do not cover, then
855 appropriate referral is made.

856 Mr. {Pallone.} Okay. Now, let me just--I am going to
857 try to summarize this last question. My concern, obviously,
858 is that I don't want this program terminated before we have
859 an opportunity to reauthorize it, and that is why we are
860 having this hearing and trying to move quickly. But in
861 preparation, you know, if reauthorization legislation is not

862 signed into law by September of next year, the program is
863 terminated. And in preparation for termination, or possible
864 termination, I understand that HHS has certain notice
865 requirements you would have to follow. Can you just tell us,
866 you know, what you would have to do? I mean, obviously, this
867 isn't what we want to happen, but I want to stress that, you
868 know, there is always that danger.

869 Dr. {Howard.} Well, it would be a nightmare for me
870 personally, and it would be a nightmare for our members, it
871 would be a nightmare for our CCE physicians. You cannot
872 abandon a patient ever as a care provider. So we must ensure
873 that that patient is taken care of somewhere, and finding a
874 place for each of our 71,942 members would be a gargantuan
875 task.

876 Mr. {Pallone.} And there are notice requirements. How-
877 -when--

878 Dr. {Howard.} Yes. We have to inform our patients
879 ahead of time that this may happen, even though we may not be
880 sure that it is happening, and certainly when it happens, and
881 all of the efforts that we can make to help them support
882 their efforts in finding additional--

883 Mr. {Pallone.} But when does that process begin? Like
884 do you have a term notice requirement?

885 Dr. {Howard.} Well, the 90-day time limit is sort of an

886 unwritten notice requirement now. It can vary state by state
887 because these are often state laws, but we have to go back
888 and look--since we have members from every state, we would
889 have to look at every state's abandonment requirements.

890 Mr. {Pallone.} All right. Thank you very much.

891 Thank you, Mr. Chairman.

892 Mr. {Pitts.} The chair thanks the gentleman.

893 Now recognize the gentleman from Kentucky, Mr.

894 Whitfield, 5 minutes for questions.

895 Mr. {Whitfield.} Well, thank you very much. And, Dr.
896 Howard, thank you for being with us this morning.

897 I want to just follow up briefly. When we think about
898 health care systems, frequently people all work with some
899 company that provides health care, or Medicare, you have to
900 be over a certain age, Medicaid, income below, the trio of
901 Tricare. So here, the common element is people from around
902 the country, whether emergency responders or volunteers, came
903 to respond to this emergency in New York, this disaster on
904 9/11/. And you touched on the criteria. I think you have
905 indicated there are 71,000-plus members enrolled in this
906 program. And is it still eligible--if I am a--someone that
907 worked there during that time, would I still be able to
908 enroll today if I am not enrolled right now?

909 Dr. {Howard.} Yes, sir, you would be. And we hope that

910 anyone listening who is not enrolled in our program, who may
911 be eligible, will call our eligibility line and sign up for
912 our program.

913 Mr. {Whitfield.} Okay. And I won't get into the
914 details, but the criteria for eligibility, I am assuming you
915 had to have been there X-days and--is that correct?

916 Dr. {Howard.} Right. They are very detailed
917 eligibility requirements spelled out in the Act itself.

918 Mr. {Whitfield.} And does your office make the decision
919 on whether or not a person is eligible or not?

920 Dr. {Howard.} Yes, sir.

921 Mr. {Whitfield.} Okay. Now, of the patients that are
922 you are caring for right now, what percent of them would you
923 say--or maybe you don't have this information, had an
924 insurance program already, they were already covered under--

925 Dr. {Howard.} Well, first of all, even if you had
926 health insurance--

927 Mr. {Whitfield.} Right.

928 Dr. {Howard.} --as a responder, you would not be able
929 to use that insurance because health insurance does not cover
930 work-related issues. For instance, if you have ever gone in
931 for an MRI or a CT scan, at the bottom of that form it will
932 say is this a result of an auto accident, is this a result of
933 a work accident. If it is, the health insurer will not pay

934 for it; they will refer you to other insurances. For
935 survivors, then health insurance could be an issue, and then
936 we recoup as much as we can--

937 Mr. {Whitfield.} Um-hum.

938 Dr. {Howard.} --from the health insurer.

939 Mr. {Whitfield.} Well, what percent would have been
940 covered under, say, the Workers' Compensation Program?

941 Dr. {Howard.} Well, theoretically, work-related
942 injuries and illnesses would all be covered, but there are
943 great difficulties for responders in accessing Workers'
944 Compensation benefits because oftentimes their condition, not
945 the original conditions where, on the event, someone had an
946 acute injury and it happened within a short period of time,
947 but some of our diseases in our program, their onset are
948 years later, and a lot of statutes draw a line--

949 Mr. {Whitfield.} Um-hum.

950 Dr. {Howard.} --and say no--

951 Mr. {Whitfield.} Um-hum.

952 Dr. {Howard.} --that is beyond our statute of
953 limitations, we will not cover something that started--

954 Mr. {Whitfield.} Um-hum.

955 Dr. {Howard.} --5 years later. So many of our members
956 are in that situation.

957 Mr. {Whitfield.} So would it be unusual that Workers'

958 Comp. may pick up part of it and then this program would pick
959 up--sort of playing a supplemental role, or--

960 Dr. {Howard.} It is not unusual. It is--many of our
961 members have had Workers' Compensation benefits given, and we
962 are in the process of recouping--

963 Mr. {Whitfield.} Right.

964 Dr. {Howard.} --from Workers' Compensation.

965 Mr. {Whitfield.} Um-hum.

966 Dr. {Howard.} But it is not the majority, or even near
967 the majority of our members.

968 Mr. {Whitfield.} Um-hum. We know some people have
969 indicated early on, I remember when there was first
970 discussion about this, that this was sort of a unique
971 program, but I know that there are health programs in effect
972 for employees at Savannah River, Paducah, Oak Ridge, and so
973 forth, which is kind of similar to this because those workers
974 were exposed to certain elements many of them were not even
975 aware of, and they came down with a lot of different cancers.
976 And so those programs are similar to this program, would you
977 say?

978 Dr. {Howard.} Yes, sir. And, in fact, we administer
979 the Energy Employees Occupational Illness Compensation
980 Program, together with the Department of Labor and the
981 Department of Energy. It is a program that bears a lot of

982 similarities to our program at the World Trade Center.

983 Mr. {Whitfield.} Yeah. And so if you worked at the
984 World Trade Center and you are covered, and you have 1 of,
985 say, 12 or 14 illnesses that you all have set out, is there a
986 presumption that, since you were there and exposed, that you
987 would be covered under this program?

988 Dr. {Howard.} Not a presumption. A physician, not in
989 the administration of the program, but in our Centers of
990 Excellence, would examine you, take your history, and make
991 the connection between the exposure history that you give
992 that physician and that health condition, and they and they
993 alone say I think the 2 are connected.

994 Mr. {Whitfield.} Right. Well, thank you very much for
995 the great job you do at NIOSH.

996 Dr. {Howard.} Thank you.

997 Mr. {Pitts.} The chair thanks the gentleman.

998 Now recognize the gentleman from Oregon, Mr. Schrader, 5
999 minutes for questions.

1000 Mr. {Schrader.} My questions have been answered, Mr.
1001 Chairman. Thank you.

1002 {Voice.} Ms. Castor.

1003 Mr. {Pitts.} All right, then the chair recognizes the
1004 gentlelady, Ms. Castor, 5 minutes for questions.

1005 Ms. {Castor.} I want to thank you, Mr. Chairman, for

1006 calling this hearing. And I would like to thank all of the
1007 first responders and survivors, and the medical professionals
1008 who take care of them, for traveling here to Capitol Hill to
1009 encourage the Congress to provide some continuity and
1010 certainty in the World Trade Center Health Program. I would
1011 like to thank my colleagues, especially from New Jersey and
1012 New York, Congressman Pallone and Congressman Lance, you all
1013 have been champions on this committee for this endeavor,
1014 along with Congresswoman Clarke and Congresswoman Maloney, I
1015 see Congresswoman King I think was still here, and the entire
1016 New York delegation, especially.

1017 I strongly support the James Zadroga 9/11 Health and
1018 Compensation Reauthorization Act because it will provide that
1019 important certainty and continuity of care from this point
1020 forward. And when you--it is interesting to see the list and
1021 understand that there are first responders and survivors from
1022 the World Trade Centre terrorist attacks all across America
1023 now. And Florida comes in right behind New York and New
1024 Jersey. So it will be very important, and I think that the
1025 folks that I represent back home will be strongly in support
1026 of taking care of their neighbors who were there on September
1027 11, and the weeks, months, and years afterwards. It is vital
1028 that we continue this specialized care for all of our
1029 neighbors, and all of the brave folks who were there on

1030 September 11.

1031 So, Dr. Howard, thank you for being here today. One of
1032 the important parts of the World Trade Center is the Zadroga
1033 Health Initiative that often gets overlooked is the funding
1034 provided for research into 9/11-related health conditions.
1035 Between fiscal year 2011 and 2014, the program funded 35
1036 projects to investigate questions about 9/11 related to
1037 physical and mental health conditions. Could you provide
1038 examples of the research that has been funded by the Zadroga
1039 Act?

1040 Dr. {Howard.} I would be happy to. We are very
1041 grateful for the original drafters of the legislation to
1042 provide money for research into the health conditions that
1043 our members face. And as I mentioned before, we have already
1044 learned quite a bit from that research. And I would like to
1045 highlight just one aspect of it, in addition to mental health
1046 and respiratory and cardiovascular, and our cancer research,
1047 our research in autoimmune diseases and others, is the
1048 research that we have done on individuals who were children
1049 at the time of 2001 attacks. There were a number of
1050 elementary schools and Stuyvesant High School, for instance,
1051 that were immediately impacted. And we have a number of
1052 those projects that are going on now, about 7 that are
1053 funded, and we are learning the effect--effects on

1054 developmental issues in the children's population. To date,
1055 we have funded \$88.5 million worth of research, and we have a
1056 significant body of research that is published in peer review
1057 journals. The World Trade Center Registry alone has
1058 published about 60 papers, and our various clinical
1059 researchers at our clinical centers have published the other
1060 papers. Our pivotal papers in cancer, autoimmune diseases,
1061 asthma, and other respiratory disorders have allowed us to
1062 provide better care, more focused care for our members.

1063 Ms. {Castor.} And are these--the results of the
1064 research, are they disseminated in an organized way to the
1065 providers and the families so that they have access--

1066 Dr. {Howard.} Yes.

1067 Ms. {Castor.} --to all of that information?

1068 Dr. {Howard.} We have membership newsletters that
1069 highlights various findings that we have from research so
1070 that they know. All of our papers are published on our--on
1071 the World Trade Center Health Programs Web site. And, of
1072 course, these are all peer reviewed publications so they
1073 appear in the science journals. And I am happy to say that
1074 the New York media picks up on those papers and reports them
1075 probably more effectively and ore widely than we can on our
1076 Web site.

1077 Ms. {Castor.} So if the Zadroga Act is not

1078 reauthorized, will these research efforts come to an end, and
1079 explain to me why that would be harmful?

1080 Dr. {Howard.} They would cease altogether, and we would
1081 lose one of, I think, the most important advantages to the
1082 program to our society, is looking at the long-term health
1083 effects from 9/11.

1084 Ms. {Castor.} Okay. And you testified earlier that
1085 health conditions often manifest themselves years later. The
1086 Zadroga Act provided funding for outreach efforts to
1087 individuals who may be eligible. We are now several years
1088 into the existence of the program, and you have successfully
1089 enrolled more than 71,000 responders and survivors. It seems
1090 to me that in addition to outreach, the continuity of care
1091 and retention of members will be important to protecting the
1092 health moving forward. That is why the Reauthorization Act
1093 here clarifies that funding may be used for continuity of
1094 care and retention. Give me your opinion on why efforts on
1095 continuity of care and retention of members will be important
1096 moving forward.

1097 Dr. {Howard.} Well, as you say, you know, our program
1098 overall, since its inception in July of 2011 with the Zadroga
1099 Act, has grown about 18 percent overall in membership, and we
1100 credit that to the wonderful contractors that we have who
1101 have done recruitment. But the other side of that is once

1102 you recruit a patient into our program, we want them to
1103 remain in our program. And every health plan loses members
1104 because we do not go and do outreach to retain them. So that
1105 is on balance now after our first 5 years. We hope to
1106 emphasize, in what we hope is our second phase, that
1107 retention of our patient population is as important as their
1108 original recruitment.

1109 Ms. {Castor.} And how do you propose to do that for
1110 first responders and survivors outside of the New York/New
1111 Jersey area, say, in the State of Florida?

1112 Dr. {Howard.} I think, first of all, you know, we do
1113 things as a team. We sit down with our representatives from
1114 survivors and responders. We have a Responder Steering
1115 Committee which is very active, meets every month, and we
1116 have a Survivors Steering Committee that is very active and
1117 meets every month. All of our ideas, suggestions, we go to
1118 them and say how are we going to do this, and together as a
1119 group we figure out how to do it. There are many modalities
1120 that we could use, and oftentimes we are told by our members
1121 what is the most effective.

1122 Ms. {Castor.} Thank you very much, sir.

1123 I yield back.

1124 Mr. {Pitts.} The chair thanks the gentlelady.

1125 Now recognizes the gentleman from Texas, Dr. Burgess, 5

1126 minutes for questions.

1127 Mr. {Burgess.} Thank you, Mr. Chairman. Thank you for
1128 having the hearing. Dr. Howard, thank you very much for
1129 being here today. And to all our witnesses on the second
1130 panel, thank you for your participation, and the people who
1131 are here in testament to the work that you have done. I also
1132 feel obligated to recognize the work of one of our
1133 colleagues, a former member, Vito Fossella, who was on this
1134 committee with us and, in fact, was responsible for my early
1135 interest in this shortly after I arrived in Congress in 2003.
1136 And it was because of that interest that I did become an
1137 early supporter of Representative King's work on this. And,
1138 in fact, I was the one who ran the bill on the Floor in the
1139 waning days of the 111th Congress, in that late lame duck
1140 session in December when the bill finally did pass on the
1141 Floor of the House.

1142 But, Dr. Howard, I am interested in--you said in your
1143 testimony that you provided for us today that certain types
1144 of cancer were added to the list of health conditions covered
1145 under this Act. Could you share with us what those cancers--
1146 what types of cancers those were--are?

1147 Dr. {Howard.} Yes. Currently covered in the program
1148 are every type of cancer, is just the short way to approach
1149 this. Every type of cancer except uterine cancer.

1150 Mr. {Burgess.} Are there--but are there those that are
1151 more--I mean what are some--what--if you were to pick the top
1152 3 malignancies, what would those be?

1153 Dr. {Howard.} I think if you looked at our 4,000 or so
1154 cases right now, probably the top ones would be thyroid
1155 cancer. There are 5 common cancers that Americans get; skin
1156 being the one, that is our top cancer. There is breast
1157 cancer, that is also a top cancer for us. There is colon
1158 cancer which is a top cancer for us. Thyroid cancer is
1159 another cancer for us. But we have seen a lot of very common
1160 cancers like that, and we have also seen some very rare-type
1161 cancers, and oftentimes from an epidemiological basis, the
1162 appearance of rare cancers is extremely helpful in terms of
1163 doing research on a population to figure out what their
1164 exposures are, causing rare cancers.

1165 Mr. {Burgess.} Sure. That speaks then also to the
1166 value in having people who have expertise in treating the
1167 types of injuries encountered because an uncommon cancer can
1168 be a difficult diagnosis to which to arrive.

1169 Dr. {Howard.} Exactly. And if they--if this cohort
1170 were distributed, we would not be able to count those. It
1171 would be very hard to find all those rare cancers if they
1172 were not--if the patients were not seen in our clinical
1173 centers, and rather, they were seeing their own personal

1174 physicians throughout the United States. It would be very
1175 difficult to do that.

1176 Mr. {Burgess.} So it provides a focus that otherwise
1177 would not be available. Just as far as just a brief comment,
1178 if you will, on the observed versus the expected cancer rates
1179 of the population that you are following, is this number of--
1180 I guess I calculate it to be 6 percent based on the number of
1181 patients you are following and the cancers you reported, how
1182 does that stack up to the general population?

1183 Dr. {Howard.} Well, that comparison, I am afraid, we
1184 can't do at this time. That would be something that we would
1185 have to wait and see what our researchers could come up with
1186 in giving us that kind of number. We are now looking at, and
1187 the Fire Department of New York City is doing some research
1188 using as a referent population to compare our World Trade
1189 Center firefighters to, another cohort that was assembled by
1190 the Institute of Firefighters not involved in World Trade
1191 Center--

1192 Mr. {Burgess.} Great.

1193 Dr. {Howard.} --so we hoped that line of research could
1194 answer your question someday.

1195 Mr. {Burgess.} So it would give them a better control
1196 if you age-match for people who are in similar occupations.

1197 Dr. {Howard.} Yes, sir.

1198 Mr. {Burgess.} Just switching gears a little bit, and
1199 you mentioned also in your testimony that, you know, you are
1200 trying to aid not just the individual members, but help grow
1201 the body of evidence and the body of information so that you
1202 can help in other situations. Are you going to be able to
1203 provide feedback to municipalities and boroughs as to the
1204 type of Workers' Compensation coverage that may be provided
1205 to members of the firefighting community, or the type of
1206 health insurance that is provided? Some of the shortcomings
1207 you mentioned were in--within the Workers' Compensation
1208 system. Are there lessons you have learned that can be
1209 extrapolated to other communities?

1210 Dr. {Howard.} Well, certainly, and I think New York
1211 State itself, its legislature and governor have already
1212 responded to this issue significantly by providing a
1213 mechanism by which responders, survivors can sign up to a
1214 program. They don't have to actually make a claim, but they
1215 can register, and then if they should develop a condition
1216 later on, that their claim would not be beyond the statute of
1217 limitations. So other states have also looked at that, and
1218 we hope that people will learn, especially from these long-
1219 duration disasters.

1220 Mr. {Burgess.} Thanks, Mr. Chairman. I will yield
1221 back.

1222 Mr. {Pitts.} The chair thanks the gentleman.

1223 Now recognize the gentlelady from Illinois, Ms.

1224 Schakowsky, 5 minutes for questions.

1225 Ms. {Schakowsky.} Thank you, Mr. Chairman. I too would
1226 like to thank all of the first responders, the survivors,
1227 those who treat them, for coming here today. For the first
1228 responders and the survivors, I am sure in addition to some
1229 health conditions that maybe more visible, that the trauma of
1230 the incident and the loss of friends, coworkers, family, is
1231 something that lingers on forever really.

1232 In Illinois, Dr. Howard, there are 13 first responders,
1233 and between 1 and 9 survivors, the way the data is kept, it
1234 is between 1 and 9, enrolled in the World Trade Center Health
1235 Program. So clearly, there is no concentration of those
1236 individuals in any kind of program of nationwide providers.
1237 So I imagine there are physicians that have 1 or 2, et
1238 cetera, so how do you maintain that--the cohesiveness of that
1239 network?

1240 Dr. {Howard.} I think that is a very good question, and
1241 I think there are a couple of ways that we do that. First of
1242 all, our Nationwide Provider Network is headed by a very
1243 capable physician who is a part of our New York-based
1244 Centers--New York and New Jersey-based Centers of Clinical
1245 Excellence. So he participates in all of our meetings, and

1246 is a great educator and teacher for the cadre of physicians
1247 that do monitoring and evaluation of that population. As you
1248 point out, a physician may have only 1 or 2. Those
1249 physicians themselves are occupationally trained, so they
1250 have the same kind of training to be able to connect exposure
1251 and health conditions as similarly situated physicians at our
1252 clinical centers.

1253 As I mentioned, we are also trying to--we have been very
1254 pleased that Medscape is helping us put together constant
1255 training, so to speak, 24/7, you can go to their Web site and
1256 get information about the latest findings from the program
1257 that may influence your practice. So even though we have a
1258 distributed network, and even though those physicians in the
1259 Nationwide Provider Program may have, as you say, 1 or 2
1260 patients, they are seeing, we want to--we want them to be as
1261 similarly situated knowledgewise as the rest of our
1262 physicians.

1263 Ms. {Schakowsky.} Great, thank you. So my
1264 understanding of the data is that there are a total of 71,000
1265 people, or approximately, that are in the program. And then
1266 it says, in a factsheet I have, that more than 30,000
1267 responders and survivors have at least 1 World Trade Center-
1268 related health condition. So there are some people in the
1269 program, I gather, that are--more than 1/2, that are simply--

1270 not simply, but that are being monitored. Is that the
1271 difference in number?

1272 Dr. {Howard.} Yes. We offer monitoring and treatment.
1273 So if you are in the monitoring program and you do not have a
1274 health condition that is included for coverage in our
1275 program, then you come on a periodic basis for monitoring.
1276 So you are not in treatment. There is no condition that a
1277 World Trade Center Health Program physician has connected to
1278 your exposure. So they are--

1279 Ms. {Schakowsky.} But the--

1280 Dr. {Howard.} --continuing to be monitored.

1281 Ms. {Schakowsky.} But the monitoring is done within the
1282 network, and there is not an additional cost to that
1283 individual for the--

1284 Dr. {Howard.} Yes.

1285 Ms. {Schakowsky.} --monitoring.

1286 Dr. {Howard.} No.

1287 Ms. {Schakowsky.} Okay.

1288 Dr. {Howard.} Our members bear no costs.

1289 Ms. {Schakowsky.} The--so the population that you serve
1290 includes some number of families of--or spouses of
1291 firefighters. Some are in that program. Survivors that may
1292 be workers in the area, residents, students, daycare,
1293 participants, et cetera. I am wondering what the breakdown

1294 is between first responders and then survivors.

1295 Dr. {Howard.} In terms of enrolled members in our
1296 program? So currently, total enrollment of the population,
1297 as you say, is 71,942. General responders, which would be
1298 police, construction workers, volunteers that came from all
1299 over--

1300 Ms. {Schakowsky.} Firefighters.

1301 Dr. {Howard.} --the United States, is about 38,953.
1302 Our fire department members are 16,569, which leaves 8,133
1303 survivors in that 71,000.

1304 Ms. {Schakowsky.} Does anybody leave the program?
1305 Aside from this issue of reenrollment, so do they have to
1306 reenroll every year?

1307 Dr. {Howard.} I am sorry?

1308 Ms. {Schakowsky.} Do they have to reenroll?

1309 Dr. {Howard.} No, no, no, you are enrolled once in our
1310 program.

1311 Ms. {Schakowsky.} Does anybody leave?

1312 Dr. {Howard.} I hope not, but I do not know that for a
1313 fact. We have members who have passed away--

1314 Ms. {Schakowsky.} Well, that is certainly--

1315 Dr. {Howard.} --but leaving--they may go to their--as
1316 has been said by Representative Pallone, they may go to their
1317 private physician to obtain health care for other nonrelated

1318 conditions.

1319 Ms. {Schakowsky.} Thank you very much.

1320 Mr. {Pitts.} The chair thanks the gentlelady.

1321 Now recognize the gentleman from New Jersey, Mr. Lance,
1322 5 minutes for questions.

1323 Mr. {Lance.} Thank you, Mr. Chairman.

1324 I don't have any questions, but I want to thank you for
1325 what you are doing, Dr. Howard. I want to thank Congressman
1326 Pallone who has worked on this issue over the course of the
1327 last more than a decade, and all of the Members of the
1328 Congress who recognize the importance of reauthorization of
1329 this legislation.

1330 This is a bittersweet hearing for me. New Jersey lost
1331 more than 700 residents. My son was playing freshman high
1332 school football, and he had a teammate whose father didn't
1333 come home. I lost a Princeton classmate in the South Tower,
1334 and my story is similar to the stories of many.

1335 I think the best speech that the younger President Bush
1336 ever delivered was on September 14 at the National Cathedral
1337 where he said that this world God created is of moral design.
1338 Grief and tragedy and hatred are only for a time. Goodness,
1339 remembrance, and love have no end. And he concluded by
1340 paraphrasing St. Paul to the Romans that no evil can separate
1341 us from God's love. What you have done is based on goodness,

1342 remembrance, and love, and that is certainly true of the
1343 first responders. And I thank all of the first responders,
1344 and I am sure this legislation will pass unanimously here, in
1345 the full committee, and on the Floor of the House.

1346 Mr. Chairman, I yield back the balance of my time.

1347 Mr. {Pitts.} The chair thanks the gentleman.

1348 Now recognize the gentleman from New York, Mr. Engel, 5
1349 minutes for questions.

1350 Mr. {Engel.} Thank you very, Mr. Chairman. And, you
1351 know, I too--there are none of us that represent New York or
1352 New Jersey and the surrounding area that wasn't deeply
1353 affected. There are 1,851 people in my district who are
1354 program beneficiaries of all you do, Dr. Howard, so we are
1355 very appreciative of it.

1356 You have answered some of my questions, but I want to
1357 try to bring out certain other things. Many of us in the
1358 aftermath--Mr. Lance just mentioned that the Friday after the
1359 Tuesday of the attacks, many of us in the delegation went to
1360 the site of the attacks. It was surreal. You just scratched
1361 your head and you couldn't believe you were really--it was
1362 like a nightmare; you couldn't believe you were really living
1363 it, and then you kind of realized every few seconds this is
1364 real. And so we walked around--other people walked around,
1365 we really weren't wearing the masks. They did give us masks

1366 but didn't really make it seem as if it was that important,
1367 so I bet a lot more people got exposure. I mean I went back
1368 several times. I don't have any ill effects, thank God, but
1369 people who are now starting to get effects, do we have
1370 trouble tracing it back to--is it difficult for people to
1371 prove so many years later that their illnesses are a result
1372 of exposure they got at the World Trade Center site?

1373 Dr. {Howard.} It is difficult. It is difficult for any
1374 of us to recall exact details of what we did a month ago, a
1375 year ago, let alone this many years ago. So for new members
1376 coming in our program, a lot of the questions that we ask
1377 about their exposure is--they are very difficult to answer.
1378 Recall is imperfect in all of us, but we take that into
1379 consideration in terms of the questions we ask and the
1380 answers they give us.

1381 Mr. {Engel.} First of all, Doctor, thank you for the
1382 great work you do. Really great work. It makes me proud to
1383 have been an original cosponsor of this legislation, and I
1384 think in all the years I have been in Congress, I have never
1385 seen our delegations more united on 1 thing, particularly the
1386 New York delegation. Since the program has been continuing,
1387 and obviously when things continue, you see what works, what
1388 doesn't work, you make adjustments, what would you change in
1389 the program? What have been some of the things that you have

1390 found difficulty with that perhaps we should consider
1391 modifying or changing to make it more efficient?

1392 Dr. {Howard.} Well, I don't think that we have found
1393 anything in the Act that has been a showstopper for us in
1394 administering the program. We look at all of the items in
1395 the Act as helping us, and we consider the Act to be a well-
1396 written document that has given us a roadmap and, as for so
1397 many years, for over a decade, we had no authorizing
1398 language, so we made it up as we went along, together with
1399 our Clinical Centers of Excellence. So we are extremely
1400 happy to have this authorizing outline for us.

1401 Mr. {Engel.} How much flexibility exists with regard to
1402 the World Trade Center Health Program's eligibility
1403 requirements? For example, if someone meets 9 out of 10
1404 benchmarks but is desperately in need of care, can exceptions
1405 be made to ensure that care gets to those who need it? How
1406 does that work?

1407 Dr. {Howard.} We look at every case on a case-by-case
1408 basis. As I said, you know, recall is not perfect this many
1409 years later, and we take that into consideration. We only
1410 decide that somebody is not eligible when we are absolutely
1411 certain that they do not fit any of the stated criteria in
1412 the Act. If we err at all, it is on the side of including
1413 someone in the program.

1414 Mr. {Engel.} In your written testimony, you noted the
1415 work that has been done through the World Trade Center Health
1416 Program to--work has been done to understand the impact that
1417 9/11 had on children, and I understand that the program has
1418 funded research projects to specifically examine the effects
1419 of 9/11 on the physical and mental health of children and
1420 adolescents. Can you talk a little bit about that?

1421 Dr. {Howard.} Well, first of all, we are very
1422 privileged to have a number of researchers in New York who
1423 are interested in this area of pediatric research for 9/11.
1424 And as I say, we have 7 projects that are funded in this
1425 area. They have not been completed as yet, so we are looking
1426 forward to those findings, so I can't report today about what
1427 those studies are showing, but it is important that the--that
1428 we have them and they continue, and we are very privileged to
1429 have a very--a couple of very good researchers working on
1430 that.

1431 Mr. {Engel.} Thank you, Doctor. And again, thank you
1432 for all you do and we are really very, very grateful to you.
1433 It affects those of us in the New York area every single day
1434 and our constituents are grateful. Thank you.

1435 Mr. {Pitts.} The chair thanks the gentleman.

1436 I understand Dr. Bucshon doesn't have any questions.
1437 The chair recognizes Mrs. Brooks from Indiana 5 minutes for

1438 questions.

1439 Mrs. {Brooks.} Thank you, Mr. Chairman.

1440 Dr. Howard, I am a former deputy mayor of Indianapolis
1441 in the late '90s, and we hosted the World Police and Fire
1442 Games in the summer of 2001, before the 9/11 attack, and
1443 there were many New York, New Jersey firefighters and police
1444 officers who perished in the attack--New York firefighters
1445 and--who perished that had participated in those games. But
1446 we also had a group called Taskforce 1 that traveled from
1447 Indiana to the World Trade Center, and we have--I have since
1448 learned, because of this hearing, that we have 53 people in
1449 the state who responded. I have 12 in my particular
1450 district, and I want to pay particular tribute, as other
1451 colleagues have done, not only to all of those from New York
1452 and New Jersey but people like individuals from Taskforce 1,
1453 engineers and technical experts and their search dogs
1454 traveled immediately that day, and continued to operate
1455 around the clock with all of their brothers and sisters in
1456 New York.

1457 There was a story several years ago about an
1458 Indianapolis fireman and a member of Taskforce 1, Charlie
1459 Gleason, who was deployed, and he said in that TV story, he
1460 said, and I quote, ``He got a little bit of that World Trade
1461 Center cough'' from that mix of the fumes, and--but he said

1462 that he would gladly answer the call again. And I understand
1463 the risk, but we have to take care of the men and women that
1464 are going, and that continue day in and day out to risk their
1465 lives for fellow citizens. And I want to thank you and all
1466 of the men and women who are here today for their service,
1467 and all the men and women around the country who did answer
1468 that call.

1469 I would like to ask you what you lose sleep about with
1470 respect to this program, what are your greatest challenges,
1471 you have answered incredibly well so many questions posed to
1472 you, but what would you say are the greatest challenges
1473 facing this program that we must reauthorize, and how do you
1474 plan to respond to those programs--

1475 Dr. {Howard.} Well, the--

1476 Mrs. {Brooks.} --or to those challenges?

1477 Dr. {Howard.} The biggest thing that worries me is that
1478 I would have to spend any amount of time, waste my time
1479 closing the program as opposed to growing the program.

1480 Mrs. {Brooks.} And the manner in which you plan to grow
1481 the program, how do you plan to do that?

1482 Dr. {Howard.} I think, you know, one of the issues that
1483 we have faced in the program, and I think I can speak for all
1484 of our Clinical Centers of Excellence, directors, and our
1485 national--Nationwide Provider Network, is when the bill

1486 passed, the President signed it on January 3, 2011, we had to
1487 be up and running July 2011. It was a very short
1488 implementation time. By a lot of work, by a lot of people,
1489 we were able to open our doors on July 1, 2011. But I think
1490 what we have done over the last 5 years, and we hope to
1491 continue to do, is quality improvement of the services we
1492 offer. Our pharmacy benefit plan, for instance, and other
1493 support for our members. We want to receive their input so
1494 that we can continue to improve the program.

1495 Mrs. {Brooks.} Thank you. Thank you for your service.
1496 I yield back.

1497 Mr. {Pitts.} The chair thanks the gentlelady.

1498 Now recognize the gentleman from New York, Mr. Collins,
1499 5 minutes for questions.

1500 Mr. {Collins.} Thank you, Mr. Chairman. And I too want
1501 to recognize all our first responders here. I think any time
1502 you come, as you have, it just helps Members of Congress in
1503 what we know is going to be a bipartisan support, as
1504 previously stated, to unanimously pass this reauthorization.

1505 But first of all, Mr. Chairman, I would like unanimous
1506 consent to enter into the record a statement from
1507 Representative Dan Donovan who represents Staten Island and a
1508 portion of Brooklyn.

1509 Mr. {Pitts.} Without objection, so ordered.

1510 [The information follows:]

1511 ***** COMMITTEE INSERT *****

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1512 Mr. {Collins.} And I would also like to recognize
1513 Representative Peter King that is with me today, and thank
1514 Mr.--or Dr. Howard for all you have done. You have pretty
1515 much answered, I think, most of our questions. I represent
1516 105 towns of western New York in the Buffalo, into the Finger
1517 Lakes area, and I believe probably most, if not all, of our
1518 volunteer fire departments, and we are mostly volunteer; we
1519 have 1 paid fire department in my district, sent individuals
1520 down to Ground Zero. That is what firefighters do and first
1521 responders. It is the community of brotherhood, and I am
1522 just happy to have learned more today about how those
1523 individuals are more than likely in your program being
1524 monitored, and I think, again, in a bipartisan way we are
1525 with you, and you are doing great work. And I don't believe
1526 you are going to have to lose any sleep about shutting this
1527 program down.

1528 With that, Mr. Chairman, I would like to yield the
1529 remainder of my time to Representative King if he would have
1530 any comments that he would like to add.

1531 Mr. {King.} If that is appropriate?

1532 Mr. {Pitts.} The chair recognizes the gentleman.

1533 Mr. {King.} Thank you, Mr. Chairman. And I do
1534 appreciate the opportunity of you allowing me to sit in and

1535 take part in the hearing. And I thank the gentleman from
1536 Upstate New York, Mr. Collins, for yielding time.

1537 I would just like to say that there is probably no more
1538 important bill that we have passed during the time, you know,
1539 that I have been in Congress than this 9/11 Zadroga Act. I
1540 had about 150 fatalities from my district, but more than
1541 that, I see every day to this day people still have rare lung
1542 diseases, respiratory illnesses, blood cancers, so this is
1543 something that is absolutely necessary to continue. And I
1544 know that people may find this might be wrong or that might
1545 be wrong, the fact is this is as effective as any program I
1546 have seen since all the time I have been in Congress, and it
1547 provides a need which is a lasting need. It is absolutely
1548 essential to go forward, and I want to thank all these men
1549 and women who are here today, the first responders, FDNY,
1550 NYPD, construction contractors, I saw--before certainly, you
1551 know, people who are residents of the area, and really
1552 everyone who answered the call that day, everyone did what
1553 they had to do, and those who are suffering these illnesses,
1554 people in the prime of life who have, again, lost their jobs,
1555 have these debilitating illnesses which have changed their
1556 lives so radically, all because they did what had to be done.

1557 So again, I thank the chairman for holding this hearing.
1558 I thank the committee for taking this issue up. I thank all

1559 of you for being here today. And I certainly thank Mr.
1560 Collins for yielding me the time. And I yield back to him.
1561 Thank you, Mr. Collins.

1562 Mr. {Pitts.} The chair thanks the gentleman.

1563 And now recognize the gentlelady from North Carolina,
1564 Mrs. Ellmers, 5 minutes for questions.

1565 Mrs. {Ellmers.} Thank you, Mr. Chairman. And thank
1566 you, Dr. Howard, for being with us. And I too want to thank
1567 all of the first responders who are here today.

1568 You know, a very emotional subcommittee hearing, and so
1569 I am going to try hard to stick to the information and get
1570 into some of these questions. Along the lines of where we
1571 are today, and I know that you have already stated, Dr.
1572 Howard, that as the number of affected first responders have
1573 come forward, those who have been determined to have cancer,
1574 how many are in existence right now, how many are with us,
1575 what number do you have of potentially affected patients who
1576 have a diagnosis of cancer?

1577 Dr. {Howard.} Well, right now, we have about 3,400
1578 cases of cancer--individual cases of cancer. Some of those
1579 cases may represent an individual that may have more than 1
1580 cancer--

1581 Mrs. {Ellmers.} Um-hum.

1582 Dr. {Howard.} --but generally speaking, that is the

1583 number of members that we have who we are--we have certified
1584 with cancer.

1585 Mrs. {Ellmers.} Now, as far as the certification
1586 process, I am just curious as to how you determine approval
1587 or denial and, you know, do you have numbers that play out as
1588 far as the possibility of being approved or denied?

1589 Dr. {Howard.} Sure, and let me just briefly explain the
1590 process. The physician who is seeing the patient makes the
1591 connection between their exposure and the health condition,
1592 in this case, cancer.

1593 Mrs. {Ellmers.} Um-hum.

1594 Dr. {Howard.} So they can say that it is caused by,
1595 contributed to, or aggravated by their exposure. That is the
1596 determination that is made by the physician.

1597 Mrs. {Ellmers.} I see.

1598 Dr. {Howard.} We don't make it in the program. That is
1599 an independent view that the physician has. Then they submit
1600 it to us--

1601 Mrs. {Ellmers.} Um-hum.

1602 Dr. {Howard.} --and we make sure that all of the
1603 supporting information is there, and then we certify it. If
1604 the supporting information isn't there, we have a question,
1605 we go back and forth--

1606 Mrs. {Ellmers.} Um-hum.

1607 Dr. {Howard.} --until we are all absolutely sure,
1608 including the determining physician and us that this is a
1609 case to be certified. Certification then means that you get
1610 your cancer covered for health care.

1611 Ms. {Ellmers.} Um-hum. And having the concentration on
1612 cancer leads me to the next question which is, do you
1613 anticipate adding other possible diseases outside of the
1614 cancer realm?

1615 Dr. {Howard.} Well, we have received to date 7
1616 petitions--

1617 Mrs. {Ellmers.} Um-hum.

1618 Dr. {Howard.} --for requests adding conditions. Two of
1619 those were cancer. The original cancer petition that
1620 Chairman Pitts referred to--

1621 Mrs. {Ellmers.} Um-hum.

1622 Dr. {Howard.} --001, and then soon after that we had a
1623 petition with regard to prostate cancer, and then 5 others.
1624 With the 5 others, we did not find sufficient scientific
1625 evidence--

1626 Mrs. {Ellmers.} Um-hum.

1627 Dr. {Howard.} --to support their addition. We get
1628 quite a few requests for adding conditions. It is hard to
1629 estimate--

1630 Mrs. {Ellmers.} Um-hum.

1631 Dr. {Howard.} --whether--what conditions we would add
1632 in the future, but we evaluate each of those requests on
1633 their scientific basis.

1634 Mrs. {Ellmers.} And then in regard to autoimmune
1635 diseases, I understand that you have made a determination
1636 that those would not be identified or added.

1637 Dr. {Howard.} Right.

1638 Mrs. {Ellmers.} And can you just expand on that?

1639 Dr. {Howard.} Right. We received a petition, our last
1640 petition, to add a large number of autoimmune diseases to our
1641 statutory list. We reviewed all of the information,
1642 including the very excellent study that had recently
1643 stimulated that petition by FDNY--

1644 Mrs. {Ellmers.} Um-hum.

1645 Dr. {Howard.} --and we found that it was insufficient
1646 at this time.

1647 Mrs. {Ellmers.} Um-hum. Um-hum.

1648 Dr. {Howard.} It doesn't mean that--and this is why we
1649 are--I emphasize so much the importance of research--

1650 Mrs. {Ellmers.} Um-hum.

1651 Dr. {Howard.} --funding in this program, is the
1652 additional work that is going on by other CCEs and our World
1653 Trade Center Health Registry to look into that--

1654 Mrs. {Ellmers.} Um-hum.

1655 Dr. {Howard.} --issue. So it doesn't mean that forever
1656 and ever--

1657 Mrs. {Ellmers.} Right.

1658 Dr. {Howard.} --it will not be added, but at this time--
1659 -

1660 Mrs. {Ellmers.} Um-hum.

1661 Dr. {Howard.} --we are not adding it.

1662 Mrs. {Ellmers.} Well, thank you, Dr. Howard. I do
1663 appreciate all of the information that you have helped us
1664 with, and I am glad to know that this is considered to be an
1665 ongoing process into the future because we don't know what
1666 the future holds for this. And again, God bless all of the
1667 first responders who are here, and your families. Thank you
1668 so much.

1669 I yield back.

1670 Mr. {Pitts.} The chair thanks the gentlelady.

1671 Now that all the members of the subcommittee have had an
1672 opportunity to ask questions, with unanimous consent I ask
1673 that the member of the full committee, Ms. Clarke, be given 5
1674 minutes for questioning.

1675 The chair recognizes Ms. Clarke.

1676 Ms. {Clarke.} Thank you very much, Mr. Chairman. We
1677 have been joined here by Congressman Gerald Nadler of New
1678 York, original sponsor of the Zadroga Act, and I wanted to

1679 yield some time to him if it is--

1680 Mr. {Nadler.} I thank you for yielding, and let me
1681 thank the chairman for holding the hearing, and the members.

1682 I simply want to say that as someone who is one of--
1683 along with Mr. King and Ms. Maloney, was one of the 3
1684 original sponsors of this bill, we struggled for years and
1685 years to pass it, I am glad to--and the history has proven
1686 the necessity of this bill, and I want to thank Dr. Howard
1687 for his wonderful service. I am glad that the chairman has
1688 called this hearing, and that, judging from the comments at
1689 the hearing, there seems to be a lot of bipartisan support
1690 for extending this bill. We know the necessity of that so I
1691 just want to urge that that be done, and that--and I thank
1692 the chairman and the committee again. Extension of this bill
1693 is essential because the diseases won't go away, and this is
1694 for both the first responders and the survivors in the
1695 community. And so I urge the extension of the bill.

1696 I thank Ms. Clarke for yielding, and I yield back to
1697 her.

1698 Ms. {Clarke.} Thank you.

1699 Dr. Howard, just following up on a couple of the
1700 questions that Mrs. Ellmers asked about the conditions. For
1701 the record, what is the process by which you can add new
1702 conditions to the program?

1703 Dr. {Howard.} Well, first of all, the administrator has
1704 the ability to add a condition on his or her own motion. The
1705 other very common route that we have seen so far is the
1706 public can petition the administrator to add a condition. As
1707 I said, we have received 7 petitions so far; 2 of those we
1708 have added the condition, the first one being cancer, the
1709 second one being a particular type of cancer; prostate
1710 cancer. The other 5 we have found insufficient evidence for.

1711 Ms. {Clarke.} I understand that the statute outlines
1712 specific timing requirements for you to respond to those
1713 petitions. Could you describe that for us?

1714 Dr. {Howard.} Right. The administrator has 60 days to
1715 respond to a petition, unless the administrator refers the
1716 petition to our Scientific and Technical Advisory Committee,
1717 and then the time frame is 180 days. So for the--for
1718 instance, in terms of the first petition on cancer, we
1719 referred that to our Science and Technical Advisory
1720 Committee. They had 180 days to make their decision.

1721 Ms. {Clarke.} Do you have any concerns with the
1722 statutory time frames under which you would have to respond
1723 to such petitions?

1724 Dr. {Howard.} Well, one of the things that the GAO
1725 report pointed out in their review of our cancer petition
1726 and--or addition of cancer was that there was no external

1727 peer review of our science that we used to justify the
1728 addition of cancer. We believe in peer review very, very
1729 much, and we want to do external peer review, but the time
1730 frame of 60 days was just--give the enormity of the task of
1731 adding all that--all those numbers of cancers, that was a
1732 very short period of time so we were unable to engage in
1733 external peer review.

1734 Ms. {Clarke.} Very well. Can you briefly tell us about
1735 the registry? It is our understanding it was created to
1736 follow individuals who were exposed to environmental toxins
1737 related to the World Trade Center terrorist attack. Tell us
1738 a bit more about the registry and why it is important--an
1739 important tool for studying the WTC-related health effects.

1740 Dr. {Howard.} The World Trade Center Health Registry,
1741 which is operated by the New York City Department of Public
1742 Health and Mental Hygiene is a vital participant in the
1743 research aspects of the program. They started very soon
1744 after 9/11. They have, interestingly enough, about 71,000
1745 members also, and I might add, I was told by the director
1746 last week that they have registrants in the registry from
1747 every congressional district, all 435. And they have
1748 produced almost 60 papers in this area. They followed the
1749 same people over periods of time, so they--every so many
1750 years, they study them to figure out what their experience

1751 is. So their research is vital to this program.

1752 Ms. {Clarke.} Do we have a sense of any of their
1753 findings so far?

1754 Dr. {Howard.} All of their findings are not only on
1755 their Web site, but also on ours. And I think some of the
1756 things that we have learned already, the issues about asthma,
1757 mental health, persistent PTSD, et cetera, have come largely
1758 from the World Trade Center Health Registry studies.

1759 Ms. {Clarke.} So you think it is important that we
1760 continue our work?

1761 Dr. {Howard.} It is absolutely vital.

1762 Ms. {Clarke.} I thank you very much, Dr. Howard.

1763 And I yield back. Thank you, Mr. Chairman. And I thank
1764 the ranking member.

1765 Mr. {Pitts.} The chair thanks the gentlelady.

1766 That concludes the questions of members who are present.

1767 I am sure, Doctor, we will have follow-up questions from
1768 members. We will send those to you in writing. We ask that
1769 you please respond promptly.

1770 Dr. {Howard.} Thank you, Mr. Chairman.

1771 Mr. {Pitts.} Thank you.

1772 That concludes our first panel. We will take a 3-minute
1773 recess as the staff sets up the witness table for the next
1774 panel.

1775 Committee stands in recess.

1776 [Recess.]

1777 Mr. {Pitts.} All right, the time of recess having
1778 expired, we will reconvene. I will ask the guests to please
1779 take their seats.

1780 {Voice.} Ladies and gentlemen.

1781 Mr. {Pitts.} Ladies and gentlemen. Ladies and
1782 gentlemen, please take your seats. The committee will
1783 reconvene. I would ask the guests to please take their
1784 seats, and I will introduce the second panel.

1785 We have 3 witnesses on the second panel, and I will
1786 introduce them in the order which they will present
1787 testimony.

1788 First, we have Dr. Iris Udasin--

1789 {Voice.} Udasin.

1790 Mr. {Pitts.} --Udasin, Medical Director, Environmental
1791 and Occupational Health Sciences Institute, Robert Wood
1792 Johnson Medical School. Welcome, Dr. Udasin. Secondly, we
1793 have Mr. David Howley, retired police officer, New York City
1794 Police Department. And finally, we have Ms. Barbara
1795 Burnette, a former detective, New York City Police
1796 Department. Thank you very much for your patience, for
1797 coming, for your testimony. Your written testimony will be
1798 made a part of the record. You will each be given 5 minutes

1799 to summarize. There are a series of lights on the table, so
1800 you will see green fist, then yellow. When red appears, we
1801 ask that you please conclude your testimony.

1802 So at this time, Dr. Udasin, you are recognized for 5
1803 minutes to summarize your testimony.

|
1804 ^STATEMENTS OF DR. IRIS UDASIN, MEDICAL DIRECTOR,
1805 ENVIRONMENTAL AND OCCUPATIONAL HEALTH SCIENCES INSTITUTE,
1806 ROBERT WOOD JOHNSON MEDICAL SCHOOL; DAVID HOWLEY, RETIRED
1807 POLICE OFFICER, NEW YORK CITY POLICE DEPARTMENT; AND BARBARA
1808 BURNETTE, FORMER DETECTIVE, NEW YORK CITY POLICE DEPARTMENT

|
1809 ^STATEMENT OF IRIS UDASIN

1810 } Dr. {Udasin.} My name is Iris Udasin, and I serve as
1811 Director of Rutgers Clinical Center of Excellence in New
1812 Jersey. We are 1 of 6 clinics in the New York/New Jersey
1813 area that provide medical monitoring and treatment for World
1814 Trade Center first responders. I am a physician who is board
1815 certified in internal and occupational medicine, and am a
1816 professor at Rutgers, and a member of the National Toxicology
1817 Panel, an expert panel that advises the National Institute of
1818 Environmental Health Sciences concerning the relationship
1819 between exposure to toxic chemicals and health.

1820 I want to thank the committee for giving me the
1821 opportunity today to testify concerning the importance of our
1822 Clinical Centers of Excellence, and for the opportunity to
1823 provide the best quality medical care through the Zadroga Act
1824 to those brave responders who have suffered from multiple,

1825 chronic and often disabling medical illnesses, including
1826 pulmonary fibrosis, sarcoidosis, asthma, gastric reflux,
1827 sinusitis, and sleep apnea.

1828 We have been monitoring World Trade Center patients in
1829 New Jersey since January 2003, and began treating patients
1830 with federal funding starting in 2007. In addition to the
1831 treatment of the aforementioned conditions, over the past 3
1832 years we have been able to use our funding under the Zadroga
1833 Act to optimize cancer care. This is critical, since as
1834 early as 2008, our responders were already showing a cancer
1835 rate that was 15 percent higher than people their age, who
1836 were not at the disaster site. This rate is only increasing,
1837 and our patients are much younger than usual cancer patients
1838 and are nonsmokers. They were highly exposed to
1839 environmental toxins as well as severe mental health trauma
1840 from what they witnessed at Ground Zero. From seeing people
1841 jumping off tall buildings to their death, or finding charred
1842 remains.

1843 Our designation as a Clinical Center of Excellence has
1844 allowed us to provide quality of care for these responders by
1845 centering all their care in a convenience location with staff
1846 members sensitive to their needs, coordinating treatment from
1847 start to finish. The combination of program-wide knowledge
1848 gained over 12 years of care delivery, in addition to my

1849 personal knowledge in New Jersey, has allowed us to
1850 understand this cohort of patients using medical and
1851 pharmaceutical resources wisely to accomplish the following
1852 objectives, which I will illustrate with specific patient
1853 examples. Coordination of care for complex cases. Diagnosis
1854 and treatment of patients considering both physical and
1855 mental health aspects of disease. Use of state-of-the-art
1856 diagnostic techniques for early diagnosis and treatment. Use
1857 of knowledge gained in our treatment of patients to allow for
1858 early intervention, enabling our skilled patients to stay at
1859 work.

1860 I am proud to share this panel with David Howley, a
1861 retired police officer, who performed many months of search
1862 and rescue work at the site. David presented with swelling
1863 in his neck in 2006, which was eventually diagnosed as an
1864 aggressive metastatic cancer of the throat. This is an
1865 unusual and rare cancer in healthy, nonsmoking Americans.
1866 However, in my center, we have seen 8 other patients with
1867 this cancer in New Jersey alone. David's treatment has
1868 required a team of doctors, including myself as primary care,
1869 the general oncologist, the radiation oncologist, the general
1870 surgeons, the ear, nose, and throat surgeons. Because of the
1871 complicated nature and location of his cancer, it has been
1872 extremely difficult to treat, but at the present time, he is

1873 tumor-free since April of 2014.

1874 The second patient I want to tell you about is a retired
1875 detective, with severe shortness of breath, chest discomfort,
1876 fatigue, and inability to perform his duties as a police
1877 officer, who was present at the 9/11 site on the date of
1878 disaster, reported being engulfed in the dust cloud, and
1879 witnessing people jumping out of buildings. He was treated
1880 by his personal physician, with 5 medications for his
1881 respiratory issues, but no other conditions. His evaluation
1882 at our center confirmed the presence of asthma, but we were
1883 also able to diagnose rhinitis, gastric reflux, sleep apnea,
1884 post-traumatic stress disorder, and panic attacks. This
1885 patient was given treatment for those conditions, and
1886 received therapy for PTSD and panic disorder. The patient
1887 was able to recognize that his panic attacks were causing him
1888 to use increased amounts of his asthma medication, and he
1889 learned to control his attacks. At his most recent
1890 examination, he no longer needs mental health medications,
1891 and is enjoying his retirement.

1892 The third patient I want to speak about works as a
1893 consultant to prevent tax fraud. An abnormality was noted on
1894 his CT scan--his chest x-ray, and he was referred for a CT
1895 scan. A small nodule was noted in November of 2014, which
1896 grew larger in January. This was evaluated by a radiologist

1897 who is an expert in interpreting lung CT scans. She was
1898 concerned about the suspicious nature of this nodule and its
1899 growth since the original CT scan. This patient was referred
1900 to our university surgeon who removed a stage 1 lung cancer,
1901 which does not need chemotherapy or radiation. And I want to
1902 say this patient is back at work. He is overseas looking for
1903 people who have cheated the government paying taxes.

1904 And finally, Rutgers University and NYU have combined to
1905 do research, finding markers for sleep apnea associated with
1906 environmental exposure. This expertise has allowed for early
1907 diagnosis and treatment of obstructive sleep apnea, enabling
1908 us to get people to work safely.

1909 My fourth patient is a pilot for a law enforcement
1910 agency, with a history of GERD and sinusitis, which are risk
1911 factors for sleep apnea. Thanks to early diagnosis, this
1912 patient has been successfully treated for his conditions, and
1913 he is fully qualified under federal standards to skillfully
1914 operate his aircraft. He asked how he could thank me for his
1915 treatment, and I said that he should continue catching
1916 terrorists.

1917 In summary, all of our patients are honored and treated
1918 by skilled clinicians. We believe we are continuing to
1919 acquire the knowledge to provide early diagnosis and
1920 treatment of emergency responders who were exposed to toxic

1921 agents and psychosocial stressors. We are striving to
1922 continue to achieve excellence and cost-effectiveness in
1923 treating our patients, as well as preparation for providing
1924 the best possible medical care for any emergency responders
1925 who were exposed to a multitude of unpredictable exposures.

1926 [The prepared statement of Dr. Udasin follows:]

1927 ***** INSERT 2 *****

|

1928 Mr. {Pitts.} The chair thanks the--

1929 Dr. {Udasin.} Thanks for the extra time.

1930 Mr. {Pitts.} --thanks the gentlelady.

1931 And now recognizes Mr. Howley 5 minutes for your

1932 summary.

|
1933 ^STATEMENT OF DAVID HOWLEY

1934 } Mr. {Howley.} Thank you, sir. First thing I would like
1935 to do is thank you for having this hearing. It is obviously
1936 very important by the amount of people that are here today,
1937 and it is both an honor and a privilege to be here and
1938 address you.

1939 There are a lot of things I would like to say about
1940 this, but I think the most important is to answer a question
1941 that you all basically posed to Dr. Howard, and that is what
1942 happens if. And Dr. Howard was wonderful in his answers, but
1943 I think I am going to be a little more blunt about it.
1944 People are going to die. The men and women that are sick,
1945 that are being taken care of now. I have only been cancer-
1946 free a little over a year. I could easily--and if it wasn't
1947 for this lady right here, I wouldn't be here at all. So to
1948 end this program, people are going to die. It is just--it is
1949 a fact. It is unquestionable, and that is what is going to
1950 happen.

1951 I was born and raised in Mr. Pallone's district, and I
1952 lived in his district once I retired, and then I moved a few
1953 years ago, and I live in Congressman Lance's district. So I
1954 have both sides of the aisle covered here. This is not

1955 something that should have any political fighting. This
1956 should be an absolute bipartisan, 435-to-0-type bill. This
1957 is a ground ball and no-brainer, as far as I am concerned.

1958 And as--the other--and the last point I would like to
1959 make, because I am going to try to keep this brief, is, I
1960 wouldn't be here, sitting here, if it wasn't for the doctors
1961 and Dr. Udasin's and her other colleagues' knowledge, skills,
1962 abilities, research. They have become the absolute experts
1963 in what is ailing us, and not just me but all the other
1964 people that are part of this program. You can't go to your
1965 regular doctor. They don't have the knowledge. They just
1966 don't. They are not bad doctors, there is nothing wrong with
1967 it, but what has happened to us because of the conditions
1968 that we were in is--has become very specific. And I didn't
1969 have a normal cancer, and there are a lot of other people who
1970 don't have normal or normal blood diseases, and because of
1971 their absolute dedication, they have come up with plans and
1972 outlines and--that they can treat and get us through these
1973 difficult diseases. And that is the most important thing is
1974 that we can have a quality of life to go forward.

1975 And I am going to leave it at that. I will be happy to
1976 answer any of your questions.

1977 [The prepared statement of Mr. Howley follows:]

1978 ***** INSERT 3 *****

|
1979 Mr. {Pitts.} The chair thanks the gentleman. And now
1980 recognizes Ms. Burnette 5 minutes for your opening statement.

|
1981 ^STATEMENT OF BARBARA BURNETTE

1982 } Ms. {Burnette.} Thank you subcommittee--Ranking Member
1983 Green, and members of the subcommittee on Health for inviting
1984 me to appear before you today.

1985 My name is Barbara Burnette, and I live in Bayside, New
1986 York. I am 52 years old, a wife, a mother, and a
1987 grandmother. With me here today are my husband, Lebral, Sr.,
1988 and my son, Lebral, Jr. I am a proud former New York City
1989 police detective. I retired from the department after 18 1/2
1990 years of service. My career came to an end because of an
1991 illness I developed from the time I served at the World Trade
1992 Center site. I served there for more than 3 weeks; about 23
1993 days in total. The morning of September 11, 2001, I was
1994 working in Brooklyn, New York, in the Gang Intelligence
1995 Division. When my fellow officers and I learned that the
1996 morning--the terrorist attacks in New York City, we rushed to
1997 lower Manhattan the fastest way possible, which was by boat.
1998 When we arrived, the towers had collapsed. The air was thick
1999 with dust and smoke. I put my hands over my mouth and noise
2000 just to breathe. My fellow officers and I worked all day and
2001 well into the night. We evacuated people from around the
2002 World Trade Center site. We directed them away from the

2003 disaster. There was so much dust, but I was not given any
2004 respirator or any kind of protection for my eyes, throat, or
2005 lungs. To--I had to wash out the debris of my eyes and
2006 throat, picking up a hose. My fellow officers and I, along
2007 with all the rescue workers and first responders, could not
2008 stop doing what we had to do. The first night I finally left
2009 the World Trade Center around 10:00 p.m., after 12 hours.
2010 Five hours later, I reported back to the World Trade Center
2011 site at 4:00 a.m. in the morning on September 12. I removed
2012 debris by using buckets and shovels, and at no time was I
2013 provided with respiratory protection. If I was not crying
2014 over what I was seeing in the room, tears streamed down my
2015 face from burning, irritating dust.

2016 I spent weeks at the World Trade Center site, shoveling,
2017 clearing away debris, searching for survivors, and later
2018 sifting for body parts of the dead. We worked side-by-side
2019 and hand-in-hand with ironworkers, construction workers,
2020 firefighters, police officers, all of us searched in the dust
2021 and removed debris together. We were searching and removing
2022 wreckage of the World Trade Center. We were working night--
2023 right on top of the burning, smoky, hot rubble. The fires
2024 never stopped burning. Air quality, we were told, was not a
2025 concern. All of us working 24/7.

2026 The work was tough and dirty, we were choking, and it

2027 was dangerous, but there was never a time when I even thought
2028 about quitting or leaving. I thought of thousands of poor
2029 Victims. If our work brought the removal and recovery
2030 efforts closer to the end, we were glad to contribute.

2031 I live with the consequences of 9/11 every day. I have
2032 been diagnosed with interstitial lung disease; more
2033 specifically, hypersensitivity pneumonitis with fibrosis in
2034 my lungs. The inflammation in my lungs interferes with my
2035 breathing, and destroys the tissues that get oxygen to my
2036 blood. My lungs are permanently scarred. I cannot move
2037 around my home or take the stairs without wheezing or gasping
2038 for breath. I start each morning connecting to a nebulizer
2039 and inhaling multiple doses of medications. I am told I will
2040 eventually need a double lung transplant. Long steroid use
2041 has caused weight gain and other--and has--and other
2042 prescription medications have caused many additional
2043 illnesses. I have been diagnosed with diabetes, high blood
2044 pressure, osteoarthritis, and rheumatoid arthritis. I have
2045 suffered partially detached retinas in both eyes, each
2046 requiring surgery. Prior to my World Trade Center service, I
2047 was in top shape. I had no history of lung disease, I never
2048 smoked, I always had a physically demanding lifestyle and
2049 career. During my time with NYPD, I worked for 5 years in
2050 the Plainclothes Narcotics Unit. These assignments required

2051 me to wear--to walk 4 miles per day, making arrests in buy-
2052 and-bust operations, and executing search warrants. I have
2053 made over 200 arrests in my career, and have assisted in
2054 hundreds more. I have been recognized by the NYPD numerous
2055 times for excellent police duty. I have also received
2056 several medals for meritorious police duty.

2057 I was born and raised in Brooklyn, New York. I played
2058 high school and college basketball. I played on the police
2059 league women's team which competed across the United States
2060 internationally. Life has become very different since I
2061 became sick. Every month, I see the doctors at Mount Sinai
2062 to receive care and renew my prescriptions. This program
2063 saves lives. It is saving my life today. It provides
2064 medical structure in my life by coordinating doctors and
2065 medications. My family does not have to suffer the financial
2066 burden of doctors' visits, copayments, deductibles, and the
2067 terrible cost of prescription medication, which I--would not
2068 be available to me without the program.

2069 I would also note that the health conditions are
2070 worsening. Many of the first responders' colleagues have
2071 been diagnosed with cancer. Many colleagues have died of
2072 cancer. The amount of dust to which we were exposed was
2073 unprecedented. Many of us fear cancer and other injuries
2074 that arise late after toxic exposure.

2075 Recently, more than 60 types of cancers have been
2076 identified by medical researchers as being directly related
2077 to the toxins found at Ground Zero. Cancer arises years and
2078 years later. For these reasons, I would urge the committee
2079 to approve the bipartisan legislation before it.

2080 Thank you.

2081 [The prepared statement of Ms. Burnette follows:]

2082 ***** INSERT 4 *****

|
2083 Mr. {Pitts.} The chair thanks the gentlelady. And
2084 thanks to all the witnesses for their testimony.

2085 I will begin the questioning by members, and recognize
2086 myself 5 minutes for that purpose.

2087 Dr. Udasin, we will begin with you. In your testimony
2088 you talk about the coordination of care that your client
2089 provides, and that you can spend time with your patients.
2090 Can you elaborate in more detail about that?

2091 Dr. {Udasin.} Since David is sitting next to me, it is
2092 a really good example. David's condition was in such a
2093 peculiar location that we had to find different surgeons that
2094 were able to get to where his cancer were--was. So this
2095 required speaking to people individually to determine who had
2096 the right expertise to actually take care of his cancer.
2097 Where he could get the right radiation, that was a big issue
2098 in David's case also because there were certain issues with
2099 how he was receiving radiation, and he could better go to one
2100 place and not go to another place. And the good news for
2101 David was that he had a supportive family to take care of his
2102 other needs, but we have had other patients not as fortunate
2103 as David where, unfortunately, we have had to coordinate
2104 getting them into things like hospice care. So my staff--and
2105 I would like to acknowledge Tracey Berspese, my

2106 administrator, who is sitting there, who helps us arrange a
2107 lot of the important things that we do with our patients.
2108 Getting them from place to place, making sure they get a good
2109 appointment and a prompt appointment.

2110 So, you know, you go into a doctor's office, and you
2111 have an abnormal test, and then you have to go and see a
2112 specialist. If you go in just by yourself, they say, oh, you
2113 can have an appointment next November. That is their next
2114 available appoint. But I can assure you, when I call up, you
2115 will be in by Tuesday. So if that answers your question.

2116 Mr. {Pitts.} Yeah. Well, just to follow up with the
2117 coordination and having time, very important for the level of
2118 care that you give. Was it possible to provide this level of
2119 care before Congress established the World Trade Center
2120 Health Program?

2121 Dr. {Udasin.} It was not possible to obtain this degree
2122 of care. Initially we had, in--the end of 2002, 2003, we
2123 just had the monitoring program, and it was very frustrating
2124 because you could find something wrong with a person and we
2125 really didn't have the resources to make sure they got to see
2126 the correct person. And I am grateful for the Zadroga
2127 funding that we have now so that we can do that.

2128 Mr. {Pitts.} Thank you. For Mr. Howley and Ms.
2129 Burnette, can you talk about your care before and after the

2130 creation of the Centers of Excellence in the Zadroga 9/11
2131 Health and--

2132 Mr. {Howley.} I--

2133 Mr. {Pitts.} --Compensation Act, and in your view is it
2134 better coordinated?

2135 Mr. {Howley.} I was thinking of a story when you just
2136 asked the doc a question. I am probably one of her original
2137 patients going back to the monitoring program back in 2003.
2138 The first time I went there, my blood pressure was basically
2139 somewhere off her chart. My sinuses were completely blown
2140 out. I had constant infections, I had GERD, which is acid
2141 reflux, and she basically refused to let me leave her office
2142 unless I went straight to my doctor to get treated for the
2143 blood pressure. And I am 6'3" and she is about 5'1", and I
2144 believed here that she wasn't going to let me out of the
2145 office.

2146 So yeah, there is a big difference. As far as--and she
2147 is just wonderful, and I am sure--and I haven't really
2148 dealt--I have only dealt with one other of the doctors at her
2149 office, and I have never been to any other offices, so I
2150 can't speak about any of them. But the doctors at--you know,
2151 are just tremendous, and they--as she was saying, when the
2152 cancer has kept coming back for me, and it has reoccurred 4
2153 times for me. You can now--she can make those phone calls

2154 now, where--and get me to the right--and when she says
2155 Tuesday, she is not kidding you.

2156 Mr. {Pitts.} Thank you. Ms. Burnette, would you
2157 respond to that, you know, as a patient in the World Trade
2158 Center Health Program, are you satisfied with your access and
2159 the care you have received, and compare before and after.

2160 Ms. {Burnette.} Yes, I am very satisfied with my care
2161 because in 2004, I started blacking-out at work and nobody
2162 knew why, and with the regular doctors I was just being sent
2163 out for different kind of tests. In the program, they send
2164 me to 1 doctor, who sends me to another doctor to make sure
2165 everything is covered. They schedule everything for you.
2166 And I think it is very important that they follow up in what
2167 is going on, and how they treat us is very well.

2168 Mr. {Pitts.} thank you. My time has expired.

2169 The chair recognizes the ranking member, Mr. Green, 5
2170 minutes for questions.

2171 Mr. {Green.} Thank you, Mr. Chairman.

2172 Mr. Howley, from your testimony I understand you have
2173 been seeing Dr. Udasin since the permanent World Trade Center
2174 Health Program was established under Zadroga. Would you
2175 explain what being able to see Dr. Udasin at the Rutgers
2176 Center of Excellence has meant to you? And I know it sounded
2177 like a little bit from the earlier question.

2178 Mr. {Howley.} That is fine. How do I phrase this in--
2179 their knowledge that they have acquired, because they have
2180 seen so many of us, when I present the next set of conditions
2181 or a former set of conditions that I had, she can tell me,
2182 Dave, go see Dr. X, Y, and Z, and not Dr. A, B, and C,
2183 because of her knowledge and skill and what she has been able
2184 to put together by seeing so many of us, she has that
2185 template, those tools in her belt--

2186 Mr. {Green.} Yeah.

2187 Mr. {Howley.} --that will send me to the right person.

2188 Mr. {Green.} Do you think you would have been in worse
2189 condition without being in the center?

2190 Mr. {Howley.} I wouldn't be here. This chair would be
2191 filled with somebody else. I would not be here. There were
2192 only 3--the last surgery I had last year, there were only I
2193 believe it was 4 surgeons that were qualified to do what I
2194 needed to get done.

2195 Mr. {Green.} Okay. Ms. Burnette, from your testimony I
2196 understand you receive medical monitoring treatment services
2197 at the Mount Sinai Clinical Center of Excellence. Could you
2198 explain what care you have received at Mount Sinai, and what
2199 it has meant to you?

2200 Ms. {Burnette.} The care I received has been excellent.
2201 They did an open lung biopsy which determined that I--which

2202 lung disease I had and how they were able to treat it, and
2203 what doctors I needed to see.

2204 Mr. {Green.} Okay. And could you explain what the care
2205 you received at Mount Sinai--I assume it is similar to what
2206 Dr. Udasin, you know, your--they are treating the whole
2207 person.

2208 Ms. {Burnette.} Yes. I have a primary doctor. They
2209 send me to individual doctors for the different diseases I
2210 have, like GERD, asthma, sinusitis, and one primary doctor
2211 coordinates all of that.

2212 Mr. {Green.} Okay. Do you think your condition would
2213 be worse if you hadn't had--didn't have access to the 9/11
2214 Health Program?

2215 Ms. {Burnette.} I believe it would be terribly worse
2216 because I was--I had that World Trade Center cough. I was
2217 not able to hold a conversation without the program providing
2218 me with the medications that I needed.

2219 Mr. {Green.} Dr. Udasin, why does this cohort of
2220 patients need the types of specialized care that is provided
2221 at the Clinical Centers of Excellence?

2222 Dr. {Udasin.} We have people with rare conditions like
2223 David that need specialists' help. We have been able to use
2224 our best university resources to get people that have seen
2225 many abnormalities on things like CT scans to get patients,

2226 like the gentleman I mentioned, to have the cancer removed.
2227 But I think really, the total--the number of conditions that
2228 we see and the complicated cases that we see, so you might
2229 have one condition and that influences another condition, and
2230 makes the third condition worse. So if you have mental
2231 health issues and you have reflux, and then you get chest
2232 pain, and you have asthma, you end up taking too many
2233 medications, and then you get a side-effect from medications.
2234 Many of the asthma medications, if you take too many of them,
2235 can precipitate heart disease. So I feel like early
2236 recognition and treatment of all the conditions correctly
2237 allows for much better outcomes for people.

2238 Mr. {Green.} It sounds like, with so many possible
2239 illnesses, misdiagnosis would be--would not be uncommon.

2240 Dr. {Udasin.} Well, that is correct. And Ms. Burnette
2241 described her sheer number of conditions. And, yes, that is
2242 the issue because you don't want to--so you treat one
2243 condition really effectively, but you kill the patient while
2244 you are doing it because she had some other condition that
2245 you ignored. And so that is what I believe we are able to
2246 do. As the primary care gatekeeper-type person, I can make
2247 sure that all the specialists are talking to each other, and
2248 making sure that the total patient is treated correctly.

2249 Mr. {Green.} Thank you, Mr. Chairman. And I think

2250 because of the complications and the exposure to not telling
2251 what, that you need to have someone who looks at the whole
2252 person and actually treats all of the illnesses that you are
2253 subject to.

2254 Thank you, Mr. Chairman.

2255 Mr. {Pitts.} The chair thanks the gentleman.

2256 Now recognize the gentleman from New Jersey, Mr. Lance,
2257 5 minutes for questions.

2258 Mr. {Lance.} Thank you, Mr. Chairman.

2259 Dr. Udasin, can you explain in a little more detail your
2260 Center of Excellence and what that means, and how many there
2261 are in the metropolitan region, and what qualifies your
2262 organization as being a Center of Excellence?

2263 Dr. {Udasin.} Well, thank you. We are part of the Non-
2264 FDNY Responder Program, and so FDNY has a separate center.
2265 We are one of the New York/New Jersey consortium which
2266 includes centers at Mount Sinai, NYU, Stony Brook, Queens
2267 College, and Rutgers.

2268 Mr. {Lance.} Mount Sinai and NYU would be in Manhattan,
2269 and--

2270 Dr. {Udasin.} Yeah.

2271 Mr. {Lance.} --and Stony Brook is on Long Island, and--

2272 Dr. {Udasin.} And--

2273 Mr. {Lance.} --Queens is obviously in Queens, and

2274 Rutgers--

2275 Dr. {Udasin.} Queens is sort of in Nassau also. It is
2276 kind of on the border over there. And--right, and we serve
2277 as a Center of Excellence in New Jersey. What makes us
2278 different, our physicians are board certified in primary care
2279 specialties, internal medicine, and occupational medicine.
2280 It is double board certified. Almost all of our physicians
2281 have at least 2 board certifications. As I said, Rutgers has
2282 an environmental center of excellence in our same building,
2283 and we do extensive work on exposure and health effects, and
2284 that happens beside--that is the rest of the faculty that I
2285 work with in Rutgers. So we have a lot of experience with
2286 exposure and illness.

2287 We have a pulmonary doctor that actually comes into our
2288 practice and sees patients with us. We have mental health
2289 people that come into our practice and see patients. And
2290 then across the street from us we have our surgeons, our
2291 gastroenterologists and a number of other specialties--
2292 specialists that we need in the Rutgers Center.

2293 By the way, we changed our name to Rutgers. We need to
2294 get that on the record that we changed from UMDNJ to Rutgers.
2295 In any event--

2296 Mr. {Lance.} That is because our state legislature has
2297 permitted the combination of the University of Medicine and

2298 Dentistry and Rutgers.

2299 Dr. {Udasin.} Right. So in any event, then I have my
2300 registered nurses who are there helping us take care of
2301 patients, making sure that histories are obtained correctly,
2302 making sure that people actually know how to use their
2303 medications. This is really very important that we have
2304 people making sure that not only medications are used, but
2305 they are used correctly. Then I have my--as mentioned, my
2306 mental health corps, then I have my administrative corps
2307 which Tracey Berspese heads, and that group of people is
2308 performing audits to make sure that everybody else is doing
2309 everything correctly. We are using our pharmacy correctly.
2310 We are doing the best that we can to keep costs down, using
2311 generic drugs, and that all of our providers and people that
2312 are writing prescriptions, that everybody is certified
2313 appropriate to do this, and that our patients actually get
2314 their medications when they get to the pharmacy. So that is
2315 part of coordination of care. And I can assure you we are
2316 performing these audits because I want to make sure that we
2317 have funding to treat our patients. Presumably you guys are
2318 going to unanimously confirm this bill, and I want the money
2319 to be there to treat our patients.

2320 Mr. {Lance.} Thank you very much, Doctor.

2321 And to Mr. Howley and Ms. Burnette, thank you for your

2322 superb public service, and certainly, we honor that public
2323 service.

2324 Ms. Burnette, what position did you play in basketball
2325 when you played basketball?

2326 Ms. {Burnette.} Point guard.

2327 Mr. {Lance.} Point guard. I was 5'8" so I never played
2328 basketball.

2329 Mr. Chairman, I have a letter from, I think, 38 members
2330 of the New York and New Jersey Delegation to Speaker Boehner
2331 and Leader Pelosi requesting early passage of this bill. I
2332 would request that it be submitted for the record.

2333 Mr. {Pitts.} The gentleman seeks unanimous consent--

2334 Mr. {Lance.} I seek--

2335 Mr. {Pitts.} --to put in the record.

2336 Without objection, so ordered.

2337 [The information follows:]

2338 ***** COMMITTEE INSERT *****

|
2339 Mr. {Lance.} Thank you, and I yield back 7 seconds.

2340 Mr. {Pitts.} The chair thanks the gentleman.

2341 Now recognizes the ranking member of the full committee,
2342 Mr. Pallone, 5 minutes for questions.

2343 Mr. {Pallone.} Thank you, Mr. Chairman.

2344 Dr. Udasin, I wanted to get into the--try to have you
2345 explain, if you will, the importance of not only the Rutgers
2346 Center but all of the centers that are part of this World
2347 Trade Program in terms of research, because there is an
2348 extensive research component, and I want you to kind of
2349 emphasize if you can how you are developing diagnosis and
2350 treatment of disorders that, you know, people might not even
2351 be aware of, and how that research and, you know, the
2352 uniqueness of the center makes that possible. Could--so
2353 could you just kind of describe how the Rutgers Center is
2354 involved in research into World Trade Center-related
2355 conditions, and how that research is improving our ability to
2356 diagnose and treat WTC-related health conditions, and the
2357 benefits of that research?

2358 Dr. {Udasin.} So answering the Rutgers only--

2359 Mr. {Pallone.} That is fine, sure.

2360 Dr. {Udasin.} --Rutgers and NYU research is, we have a
2361 lot of sleep apnea experts in those 2 centers, and what I am

2362 really proud to say is that between our laboratory
2363 toxicologists and our sleep experts, we have developed
2364 certain markers that we are seeing in certain of our
2365 patients. Dr. Sundaram, one of our sleep experts, presented
2366 this at the recent American Thoracic Society meetings, that
2367 certain markers were developed that certain people can be
2368 predicted possibly to have sleep apnea. And this is really
2369 important because these are inflammatory markers, and these
2370 people at 9/11 site were exposed to all kinds of toxins that
2371 can cause inflammation. And so because of that association
2372 between environmental exposures and inflammation, we have
2373 been able to find people a lot sooner, get them treated. And
2374 for people to think about sleep apnea and the environment,
2375 because traditionally sleep apnea was thought of something
2376 that you had to be enormously obese to get, and we have
2377 patients that are not quite playing point guard, but are in
2378 awfully good shape that have sleep apnea. And we are able
2379 to--as I said, we--because of our occupational expertise,
2380 sleep apnea is a very serious condition. There was somebody
2381 who died recently, a celebrity, on the New Jersey Turnpike
2382 because a bus driver fell asleep. And we have a lot of our
2383 patients who have to drive commercial vehicles, operate
2384 planes, operate the subway, operate all kinds of heavy
2385 equipment, and it is really good that we are able to treat

2386 them and keep them safe and awake. And I feel like that is
2387 one thing our research has accomplished, which is not only
2388 applicable to our patients, but it is applicable to other
2389 people with environmental exposures.

2390 Mr. {Pallone.} Let me--I appreciate that. The other
2391 thing I wanted to--if you could get across is how we can
2392 expect an increase among the population that--of these 9/11-
2393 related conditions. In other words, my understanding is as
2394 time goes on, we find more cancers, more disorders, you know,
2395 as people get older, that maybe didn't exist before and that
2396 have to be--and that now we are finding through your research
2397 or others in these centers that are related to 9/11 that we
2398 didn't know about before.

2399 Dr. {Udasin.} So I want to say that certain kinds of
2400 malignancies--poietic malignancies, have very short latency
2401 periods, and you would expect to see something like that
2402 within just a couple of years after exposure to toxins, but
2403 other toxins like asbestos have much longer latency periods,
2404 and they might be seen later on and at a different time.

2405 And if I could use just a few minutes to also answer a
2406 question that you asked Dr. Howard earlier about mistakes
2407 made by providers outside of the program. If I could just
2408 add that we have found in the program that people have been
2409 undertreated by local providers for various cancers, for

2410 various severe lung conditions like pulmonary fibrosis, and I
2411 do want to say, even though that wasn't exactly the question
2412 you asked, I do want to say that we have been able to improve
2413 the health care by tuning up, by getting better diagnostic
2414 services to our patients than they were able to get from some
2415 of the local people.

2416 Mr. {Pallone.} Thank you very much.

2417 Thank you, Mr. Chairman.

2418 Mr. {Pitts.} The chair thanks the gentleman.

2419 That concludes the questions of the members. They will
2420 have follow-up questions in writing. We will submit to the--
2421 those to you, ask that you please respond promptly.

2422 I would remind members they have 10 business days to
2423 submit questions for the record. And they should submit
2424 their questions by the close of business on Thursday, June
2425 25.

2426 Thank you very much for sharing your personal
2427 experience, for your excellent testimony. The committee will
2428 take up this legislation, I assure you, and act on it. And
2429 you have performed a public service by being here today.
2430 Thank you very much.

2431 And without objection, the subcommittee is adjourned.

2432 [Whereupon, at 12:43 p.m., the Subcommittee was
2433 adjourned.]