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COMMONWEALTH OF PENNSYLVANIA
HOUSE OF REPRESENTATIVES
HOUSE AGING AND
OLDER ADULT SERVICES COMMITTEE

MAIN CAPITOL BUILDING
ROOM 60 EAST WING
HARRISBURG, PENNSYLVANIA

WEDNESDAY, NOVEMBER 18, 2009
9:04 A.M.

IN RE: PUBLIC HEARING ON

IMPROVING END-OF-LIFE
EXPERIENCES FOR PENNSYLVANIANS

BEFORE:

- HONORABLE PHYLLIS MUNDY, CHAIRMAN
- HONORABLE TIM HENNESSEY
- HONORABLE KAREN BOBACK
- HONORABLE MICHELE BROOKS
- HONORABLE VANESSA LOWERY BROWN
- HONORABLE PAUL J. DRUCKER
- HONORABLE MAUREE GINGRICH
- HONORABLE WILLIAM C. KORTZ, II
- HONORABLE DEBERAH KULA
- HONORABLE BARBARA McILVAINE SMITH

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3 HONORABLE MARGUERITE QUINN
HONORABLE EDDIE DAY PASHINSKI
4 HONORABLE STEVE SAMUELSON
HONORABLE ROSEMARIE SWANGER
5 HONORABLE KEN SMITH
HONORABLE RANDY VULAKOVICH

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ALSO PRESENT:

CHARLES QUINNAN, MAJORITY EXECUTIVE DIRECTOR
SHARON SCHWARTZ, MINORITY EXECUTIVE DIRECTOR
SUZANNE CHADWICK, LEGISLATIVE ASSISTANT

BRENDA S. HAMILTON, RPR
REPORTER - NOTARY PUBLIC

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10	AND COMMUNITY HEALTH, UNIVERSITY OF	
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2 P R O C E E D I N G S

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4 CHAIRMAN MUNDY: Good morning, everyone.
5 Good morning. We were just slightly delayed this
6 morning. Not a problem. And it's good to have
7 some of our members here on what turned out to be a
8 nonsession day.

9 I'd like to welcome you to the House
10 Aging and Older Adult Services Committee. This is
11 a public hearing on end-of-life issues.

12 And the purpose of the hearing is to
13 discuss the report and recommendations issued by
14 the Governor's Task Force for Quality at the End of
15 Life, improving end of life experiences for
16 Pennsylvanians.

17 The report brings to light some troubling
18 findings. Less than a quarter of Pennsylvanians
19 die at home despite the fact that an overwhelming
20 majority would prefer to do so. Hospice use among
21 Pennsylvanians is low with only 25 -- 21 percent of
22 those age 65 and older having used Hospice in the
23 last year of life.

24 Less than one percent of health care
25 providers in the Commonwealth are certified in

1 palliative care, and pain is often managed poorly
2 despite the ready availability of safe and
3 effective treatments.

4 As a committee, I believe it's important
5 that we utilize all available resources in our
6 efforts to enhance the well being of older
7 Pennsylvanians. All too often studies and reports
8 end up on the shelf and never get the attention
9 that they deserve.

10 So I'm glad we have the opportunity today
11 to examine the important work of the task force,
12 and I look forward to a productive dialogue.

13 Chairman Hennessey, would you like to say
14 a few words?

15 REPRESENTATIVE HENNESSEY: Thank you,
16 Madam Chairman.

17 I'm pleased to be with you here today to
18 listen and learn from experts who practice in
19 end-of-life situations.

20 Many of us have probably experienced
21 family situations where we recognize the sad
22 reality of losing a loved one. And that is a
23 singular event and has emotional consequences that
24 we were forced to deal with.

25 But sometimes the onset of death really

1 is accompanied by the distress of an extended end
2 of life. That's excruciating not just for the
3 dying but for the family members who have to sit
4 and see and witness this on a day-to-day basis.

5 Add to that the -- the emotional
6 trauma -- add to the emotional trauma the financial
7 burdens that people have to recognize, and
8 sometimes you destroy a nest egg that you intended
9 for a surviving spouse.

10 So you can see the consequences of this
11 kind of thing can play out on several levels.

12 As individuals none of us can really be
13 prepared for that; but as a Commonwealth, we do
14 have the ability to help our fellow citizens by
15 drawing upon the shared experiences of all our
16 citizens.

17 We can make difficult situations more
18 manageable and more predictable and less
19 Draconian. And today's hearing will give us an
20 insight into what the future can hold for all of us
21 and for our viewers who are watching us across the
22 Commonwealth and hopefully help us to prepare to
23 manage the difficult or -- difficult ordeal if and
24 when it comes.

25 Thank you, Chairman Mundy, for convening

1 this hearing and thanks to our presenters.

2 CHAIRMAN MUNDY: Would the members of our
3 committee please introduce yourselves to the
4 audience.

5 REPRESENTATIVE DRUCKER: Are you talking
6 to me? I'm -- I'm Paul Drucker, 157th District.
7 That's Chester and Montgomery County.

8 REPRESENTATIVE McILVAINE SMITH: Barb
9 McIlvaine Smith, Chester County.

10 REPRESENTATIVE WILLIAMS: Jewell
11 Williams, Philadelphia County.

12 REPRESENTATIVE MILNE: Duane Milne,
13 Chester County.

14 REPRESENTATIVE BROOKS: Michele Brooks,
15 portions of Crawford, Mercer, and Lawrence
16 counties.

17 REPRESENTATIVE VULAKOVICH: Randy
18 Vulakovich, Allegheny County.

19 REPRESENTATIVE SAMUELSON: Steve
20 Samuelson from Lehigh Valley.

21 MR. QUINNAN: Chuck Quinnan, Democratic
22 executive director to the committee.

23 CHAIRMAN MUNDY: Phyllis Mundy from
24 Luzerne County. I'm chairman of the committee.

25 REPRESENTATIVE HENNESSEY: Tim Hennessey

1 from Chester County.

2 MS. SCHWARTZ: Sharon Schwartz,
3 Republican executive director for the committee.

4 REPRESENTATIVE SMITH: Good morning. Ken
5 Smith, Lackawanna County.

6 REPRESENTATIVE PASHINSKI: Representative
7 Eddie Day Pashinski, Luzerne County.

8 REPRESENTATIVE MIRABITO: Rick Mirabito,
9 Lycoming County.

10 REPRESENTATIVE KULA: Deberah Kula,
11 Fayette and Westmoreland County.

12 REPRESENTATIVE KORTZ: Good morning.
13 Bill Kortz, 38th District, Allegheny County.

14 REPRESENTATIVE BOBACK: Karen Boback,
15 parts of Luzerne, Columbia, and Wyoming Counties.

16 CHAIRMAN MUNDY: Thank you, members. Our
17 first testifier this morning is Dr. Joseph Straton,
18 assistant professor, family medicine and community
19 health from the University of Pennsylvania and
20 chief medical officer of Penn Wissahickon Hospice.

21 Dr. Straton, if you'd please take your
22 seat and you can begin whenever you're ready.

23 DR. STRATON: Good morning, everybody.

24 REPRESENTATIVE PASHINSKI: Good morning.

25 DR. STRATON: Good morning, everyone.

1 And thank you very much for inviting me to present
2 today.

3 Thank you, Chair -- Chairwoman Mundy and
4 all the members of the House Aging and Older Adult
5 Services Committee.

6 It is -- it's a great honor to be here
7 with you and -- and really to be with you to talk
8 about my great passion in life, which is taking
9 care of people at the end of life.

10 And as -- as you described, I'm an
11 assistant professor at the University the
12 Pennsylvania. I'm a palliative care and hospice
13 physician, and my whole career is really devoted to
14 taking care of people at the end of life and making
15 this experience great.

16 And I, you know, think very often as I
17 meet people who may not be as familiar with the --
18 you know, with this type of care and work. You
19 know, especially medical students and nursing
20 students and others.

21 I'm always asked, how do you do this?
22 How do you spend your life with people who are
23 dying?

24 And -- and what I've learned is -- is to
25 help people understand that I don't spend my life

1 with people who are dying. You know, quite the
2 contrary. I spend my life with people who are
3 living.

4 And -- and so I think very often when we
5 talk about the end of life, it -- it has this
6 feeling of -- of, you know, this initial feeling of
7 sadness or difficulty. But, you know, it's really
8 quite the opposite.

9 I spend my time with people who are
10 really living much more fully than I live my life
11 on a day-to-day basis because their time is very
12 limited and -- and they're not really focused on
13 the things that I focused on this morning of, you
14 know, darn, I spilled coffee on my suit.

15 They -- they're really focused on, you
16 know, I've got a limited amount of time. I got to
17 make the most of it. I got to be with my kids, my
18 grandkids, my parents, you know, really focused on
19 the most important things in life.

20 And -- and the work that I do and I think
21 the work that we're all focused on this morning is
22 how do we assist people to make that time as great
23 as it can be, and -- and just my own personal
24 story, I got into this line of work because my
25 brother died when he was young. He was 26. I was

1 24. He was being taken care of at the -- at MCP,
2 the Medical College of Pennsylvania, in
3 Philadelphia, and he had -- he had a terrible brain
4 tumor.

5 But we had together in the hospital my
6 whole family, my brother, my younger brother, my
7 mom, my dad, other family members. We had six
8 weeks together in -- in the hospital where we all
9 got to take care of him, share memories.

10 And as terrible and tragic as that was,
11 some of the best six weeks of my life, of my
12 family's life, and we all reflect, and what made it
13 great, was the care that we received from the
14 doctors, nurses, social workers, chaplains,
15 everybody who was around us who made this
16 experience -- made this awful experience a very,
17 very positive and memorable experience for us.

18 And so, again, not -- not to focus on
19 myself or my family but -- but just to note that,
20 you know, the work that we're doing and the --
21 really the important work that we can do as -- as a
22 Commonwealth is to make sure that everybody has a
23 great experience and so that everybody can, as
24 they're living out final days, weeks, and months,
25 know that they have all the support they need to

1 make this experience positive and that their family
2 members will, just like me, forever look back on
3 these experiences as, you know, incredibly
4 important memorable and really life-changing
5 events.

6 And as Chairwoman Mundy introduced,
7 that's not the way -- that's not the experience
8 that many people have right now. Many people feel
9 abandoned. They feel alone. They're -- they're in
10 pain. They're suffering from other symptoms or
11 other distress.

12 And -- and really our work is to make
13 sure that -- that we're using all the resources
14 that we have available to us and that are really
15 already available to people to make sure that --
16 that these experiences are the opposite of what
17 they are now. They're not painful. They're not
18 lonely. They're -- they're comforted. Their
19 symptoms are incredibly well managed and that these
20 are very, very positive experiences.

21 And, again, it's a great honor to present
22 to you, and I'm so grateful for the opportunity so
23 that we can work together in any way -- in every
24 way that we can to change these experiences for
25 people.

1 The Task Force on Quality at the End of
2 Life did a tremendous work generating the reports
3 that they generated to summarize the information
4 that's available about the current state of affairs
5 and to suggest recommendations about how we can
6 change things.

7 The reports came up with 160
8 recommendations, each of which is important.

9 And in my comments I'd like to really
10 focus on -- on your assistance in -- in leading the
11 improvement to access the services that are
12 available. There's so many services that are
13 already available with palliative care programs and
14 hospice programs throughout the Commonwealth.

15 And one of the key things that I think we
16 need to do is not create new services but just
17 improve access to the services that already exist.

18 And we really need to improve access to
19 these service, and especially for people -- for
20 aging -- for Pennsylvanians who are 65 years and
21 older.

22 Well, you know better than I that people
23 in this age group make up about 16 percent of the
24 state population, but four out of five people who
25 die in the state, 80 percent of the people who die

1 in the state, are 65 years and older.

2 And so by improving end-of-life services
3 for everyone in the state, we're really improving
4 them for older Pennsylvanians.

5 And, in addition, Pennsylvanians who are
6 65 years and older are not dying suddenly. They're
7 not dying unexpectedly. They're, as the report
8 shows, they're dying from chronic illnesses.
9 They're dying from illnesses such as cancer, heart
10 disease, lung diseases such as emphysema, from
11 kidney disease.

12 So said another way, people aren't dying
13 from these diseases. They're living with these
14 illnesses. And -- and our job is that, as they're
15 living with these illnesses, that we can make sure
16 they have all the support they need, that in the
17 final days, weeks, and months that their
18 experiences are great.

19 And -- and these are the illnesses that
20 can most benefit from hospice and palliative care
21 services.

22 When I teach medical students and nursing
23 students, people often say, what the heck is the
24 difference between palliative care and hospice?
25 And it's very confusing because palliative care and

1 hospice are really focused on the same thing.

2 They're focused on improving quality of
3 life by reducing distress and really by
4 aggressively managing symptoms and other forms of
5 distress. So they really do the same thing.

6 Palliative care services are -- are not
7 as well defined as hospice services. We have three
8 hospitals in our health system. We have palliative
9 care services in all of the three hospitals, and
10 each service looks different.

11 Hospice services are much more uniform
12 because they're really well defined by Medicare and
13 other insurance programs. So I think of hospice
14 programs as insurance defined programs of providing
15 palliative care.

16 And so all hospice programs look pretty
17 similar. They all have physicians, nurses, home
18 health aides, social workers, chaplains,
19 volunteers, and many others, and provide a pretty
20 set -- set of services, standard set of services,
21 to people who enroll in them.

22 Palliative care programs provide similar
23 services, but -- but in very disparate ways.
24 They're just not as well defined because it's not a
25 insurance defined program.

1 I'll focus a lot of my talk or
2 presentation about hospice because hospice is so
3 well-defined and it's similar throughout all of the
4 counties you represent. And -- and really there
5 are great services available in all of your
6 legislative districts.

7 What we need to do is make sure that
8 people are aware of these services and improve
9 access to them. And so I think that's the way that
10 we can get the biggest bang for the buck, is to
11 just take the services that are already available
12 and make sure that people are aware of them.

13 And so just by doing that we can
14 dramatically improve the end-of-life experience for
15 older Pennsylvanians.

16 And so improving access is critically
17 important for two reasons. First and foremost,
18 there are numerous studies that demonstrate the
19 positive impact that hospice and palliative care
20 have on the quality of life for people who are
21 dying and for their families.

22 And, second -- a second reason that's
23 critically important, or at least that I see, is I
24 see the effect of it every single day. As the lead
25 physician for Penn's hospice, I oversee the daily

1 care for 250 people in five of the counties that we
2 already spoke about here today.

3 The large majority of these patients are
4 65 years and older. Many of these people or most
5 people are living at home. Many people are living
6 in nursing homes. Many people are living in
7 inpatient facilities.

8 And every day, every single day, my team
9 and I are thanked by patients and families for all
10 the physical care they received. For all the
11 emotional support that they received, and we're
12 told every single day that -- how our services help
13 somebody live more fully and helped their family
14 feel confident and supported.

15 And every day we're told by people we
16 wish we had known about this sooner. Had we known
17 about it sooner we would have enrolled in hospice
18 sooner, we would have taken advantage of these
19 services sooner.

20 As the reports demonstrate, about 30
21 percent of people enroll in hospice in the last
22 seven days of life. About half of people enroll in
23 hospice for only 20 days of life. And the Medicare
24 hospice benefit provide services 180 days or
25 longer.

1 The recommendation is -- or people can
2 enroll in the last six months of life, but most
3 people only enroll in about the last two or three
4 weeks of life.

5 By us getting the word out about these
6 services that are provided to people that are
7 already paid for, that cost us nothing in addition
8 to what's already provided, by just getting the
9 word out, people can enroll sooner and really
10 benefit from these services.

11 And so I think two simple and inexpensive
12 ways to improve access to hospice and palliative
13 care services throughout the Commonwealth are
14 these.

15 First, that as a committee, I think that
16 you have the capability to lead an effort to
17 promote -- to promote awareness throughout the
18 Commonwealth. And so just by promoting -- you
19 know, if there's a way that this committee can lead
20 the promotion of awareness of these services, then
21 we can just -- we can increase access to services
22 that are already paid for through insurance
23 benefits or through Medicare.

24 Currently, Pennsylvanians find out about
25 hospice and palliative care services by word of

1 mouth. They find out from their friends, their
2 family members, their physicians. And as -- as
3 we've already known people find out too late. This
4 is not an effective way of finding out about it.

5 So I think as a committee there may be a
6 way that we can lead an awareness campaign
7 throughout the state so people can find out about
8 this sooner.

9 And by finding out about these services
10 sooner, I think it's the second important task
11 ahead of us, is that we would be able to dispel the
12 myths about hospice care or end-of-life decision
13 making.

14 The more people know about hospice and
15 palliative care services the more likely they are
16 to talk about it, the more likely they are to talk
17 with their physicians and clinicians about it, and
18 to say in the office, you know, doctor, I heard
19 about hospice. Sounds like a great thing. You
20 know, what is it?

21 And -- and that way doctors and other
22 health care providers would have the opportunity to
23 counsel their patients about the type of services
24 that are available and also to help promote
25 autonomy for their patients. Where the patients

1 and the doctors could talk about, you know, what
2 somebody's preferences are, how they would like to
3 live out their days, and how we can take that
4 autonomy or maintain the autonomy by providing
5 decision-making capacity for family members and by
6 making sure that they enroll in the right programs
7 and get the services they need.

8 So I think, again, it's -- I want to be
9 very clear that it's of the utmost importance that
10 we help people prepare for the end of life and that
11 the best way we can do this is to inform people
12 about the services that are available and to
13 educate patients to have conversations about their
14 wishes with clinicians and with their family
15 members.

16 I want to thank you once again for
17 inviting me to testify before your committee, and
18 I'd be happy to answer any questions that you
19 have.

20 Thank you very much.

21 CHAIRMAN MUNDY: Thank you, Dr. Straton,
22 and thank you for your work in this area.

23 Before I open it up to the other
24 committee members, I wanted to ask you, as you were
25 talking, it struck me that, you know, we as

1 legislators -- you're saying we as legislators, we
2 as a committee, should make people aware of these
3 services, and it seems to me that the most
4 effective source of information about what's
5 available at end of life would be the medical
6 community. Because obviously that's where people
7 go when they have an illness or when they, you
8 know, are experiencing symptoms, pain, et cetera.

9 What -- what is the medical community
10 doing to inform itself and -- and become better
11 counselors in terms of what's available for people
12 in palliative care?

13 DR. STRATON: So they're a lot of
14 initiatives that are currently undertaken so that
15 the medical -- we as a medical community can be
16 informed and that we can be very proactive in
17 talking with patients and families.

18 The National Hospice and Palliative Care
19 Organization and the American Academy of Hospice
20 and Palliative Medicine are aggressively working to
21 educate physicians throughout the nation about
22 end-of-life services. So that primary care
23 physicians and specialists are all aware of what's
24 available.

25 And also we're training people in how to

1 have conversations about the end of life.

2 Physicians are people. You know, we're comfortable
3 talking about the things we're talking about. The
4 things we're uncomfortable talking about we avoid.

5 And --

6 CHAIRMAN MUNDY: Us, too.

7 DR. STRATON: Yes. I hope my wife isn't
8 watching on television. But, right. But if I'm
9 going to be late from work, I sometimes avoid, you
10 know, being proactive in talking about that.

11 And we -- and so I think -- so a lot of
12 what we're doing is -- is training physicians and
13 nurses and others how to talk about end-of-life
14 issues so that we're comfortable about bringing it
15 up and so it's not something that's left to a
16 crisis.

17 And within the state, the Pennsylvania
18 Hospice Network is very engaged in bringing
19 hospices together throughout the -- throughout the
20 Commonwealth to -- to work on initiatives
21 throughout the Commonwealth.

22 So I think there's much that's being
23 done. Not enough certainly that's being done in
24 the medical community.

25 And one thing that's not being done in

1 the medical community is kind of bringing people
2 together, doing public service announcements or,
3 you know, other initiatives to make not just
4 patients aware but people throughout.

5 You know, it's one thing to educate
6 patients, I think it's another thing to just
7 educate people. You know, people like all of us
8 who go to the supermarket and, you know, walk
9 through town to be more aware of hospice.

10 So it's not just a medical thing. It's
11 just a life thing.

12 CHAIRMAN MUNDY: Thank you. And the
13 other thing that struck me, you talked about some
14 of the myths about hospice care. Could you give us
15 some examples of what you perceive as myths?

16 DR. STRATON: I -- a close friend of my
17 family has metastatic breast cancer and -- and
18 she's not responding to chemotherapy. She's in
19 clinical trial.

20 Another way of describing her is she's
21 dying from metastatic breast cancer. Because she
22 has widely metastatic breast cancer. She's not
23 responding.

24 She called me up the other day and said,
25 gosh, should I be -- is it time for me to be

1 thinking about palliative care? And -- and I
2 thought, boy, four years ago was -- you know,
3 palliative is aggressive symptom management
4 throughout the course of illness and you should be
5 getting that the whole time you're getting
6 chemotherapy and everything else.

7 I think what she was saying was, am I
8 dying? Should I be thinking about hospice?

9 But even she, you know, who I'm a close
10 friend of hers and this is what I do for a living,
11 she avoided calling me because she didn't want to
12 think about these issues.

13 And -- and even when she had the nerve to
14 call me she brought it up in -- in this kind of
15 couched or coded language.

16 One of the myths? I think people feel
17 like once hospice is called in they're dying in the
18 next couple of days. So when a clinician finally
19 has the nerve to bring up hospice, I think the myth
20 is that people feel like this is coded language,
21 oh, my gosh, I'm dying tomorrow.

22 As opposed to, you can bene -- you
23 can bene -- your Medicare pays for this for 180
24 days at least. So that's one of the myths.

25 I think that there are myths about

1 morphine that, oh, if the -- if the doctors and
2 nurses are suggesting morphine that means they're
3 trying to hasten my death. That morphine is
4 equivalent to euthanasia.

5 Which I -- patients will ask me that or
6 family members will ask me that. And I have to
7 first remind them it's actually illegal for me to
8 do euthanasia. And -- and so, oh, great, okay.

9 So I think there are myths about
10 euthanasia, myths about morphine, myths about
11 hospice itself.

12 There are -- I hate to bring it up
13 because I don't want to derail our conversation,
14 but there's the whole myth that when Medicare tried
15 to pay physicians to have conversations about
16 preferences about end-of-life care -- excuse me --
17 that suddenly that was a death panel.

18 So I think that there are -- those are
19 among the myths; that hospice means death; that
20 morphine means death, that having conversations
21 about end-of-life care is equivalent to a death
22 panel.

23 So I carried on. I'm sorry. There are
24 many myths.

25 CHAIRMAN MUNDY: Oh, no. That was very

1 interesting. I really appreciate that. Because
2 I -- you know, I think the -- the myths that you
3 talked about are exactly what deter people from
4 getting this very important and -- and helpful
5 treatment.

6 When I -- when my mother was dying a
7 couple of years ago in -- she was in hospice for
8 the last week. She had been in a nursing home for
9 many years.

10 And one of the issues that arose was the
11 issue of the nursing home rules and regulations.
12 Now this was in Florida, not Pennsylvania.

13 But nursing home rules and regulations
14 versus hospice rules and regulations. And my
15 hospice nurse was telling the family that there are
16 things that I should be able to be doing for your
17 mother that I can't do because she's in the nursing
18 home.

19 Are there similar conflicts here in
20 Pennsylvania and could you just briefly touch on
21 those?

22 DR. STRATON: There are. And Joan Teno
23 at Brown University has done a tremendous amount of
24 work in this area. And in our own hospice we've
25 hired a geriatrician and we have a team that's

1 dedicated to the nursing homes be -- to work within
2 the culture of a nursing homes because they're a
3 community. They have their own specific culture,
4 each one.

5 And -- and we've learned to provide
6 effective care we need to be, you know, welcomed
7 into the community as knowledgeable members.

8 But some of the -- some of the challenges
9 of people dying in nursing homes, even though a
10 large percentage of older adults die in nursing
11 homes, and there's a great chance that we're all
12 going to die in nursing homes, that nursing homes
13 are not designed as places where people die. They
14 were designed as a place where people go for
15 restorative care.

16 And so nursing homes in their -- in their
17 regulations, in the -- in the groups that oversee
18 nursing home care, if people are losing weight,
19 nursing homes, you know, get -- they get dinged for
20 that. If people are -- develop ulcers or wounds on
21 their body, nursing homes -- the -- the accrediting
22 agencies, you know, they can get deficiencies for
23 that. If people die, nursing homes can get
24 deficiencies for that.

25 Death in a nursing home is -- and dying,

1 the process of dying is seen as really a negative
2 outcome.

3 And so nursing homes in many states, and
4 here as well, they try to prevent people from
5 losing weight. So if somebody can't eat, they get
6 a -- they get a tube so they can get tube fed.

7 And if -- if people are -- if people are
8 dying and they're too ill to get out of bed,
9 sometimes nursing homes will say but we're -- by
10 regulation we have to get you out of bed.

11 So we'll get dying people into a chair
12 and bring them into community rooms so they can,
13 you know, be this public -- you know, they can sort
14 of die publicly rather than privately.

15 And so -- so when -- two -- I think two
16 ways to intervene on a local level, each of us, you
17 know, as a hospice and palliative care community,
18 can work within the culture of the nursing home to
19 help think through ways that they can get -- not
20 get around -- make sure that people get the care
21 they need and the nursing home doesn't get
22 deficiencies for people dying or losing weight.

23 And then I think from a state's
24 standpoint, to make sure that the way we measure
25 nursing homes doesn't get in the way of end-of-life

1 care.

2 CHAIRMAN MUNDY: How about medications?

3 DR. STRATON: Morphine, so morphine is a
4 great medicine for pain, for shortness of breath.
5 It's a great medicine for many of the things that
6 we will all face as -- as we are dying.

7 Morphine is hard to -- to get in many
8 nursing homes. It's hard in many nursing homes to
9 get what we call as-needed medicines for -- for
10 someone to see that someone has a symptom and then
11 give them medicine as needed.

12 And so many of the medicines that we
13 usually order in the home as needed, we would tell
14 a family member if your -- you know, if your
15 mother, father, son, has shortness of breath, has
16 pain, please give this medicine as needed.

17 In the nursing home, we need to order
18 them as standing medicines. You must give this
19 every four hours because it's difficult to give
20 as-needed medicines in nursing homes.

21 I wish I could think of a statewide fix
22 for these things. In my experience it's really a
23 nursing-home-by-nursing-home, hospice-by-hospice
24 collaboration to make these cultural shifts.

25 CHAIRMAN MUNDY: Thank you very much,

1 Dr. Straton. I appreciate your answers.

2 Representative Pashinski has a question.

3 REPRESENTATIVE PASHINSKI: Thank you very
4 much, Madam Chairman.

5 And thank you very much, doctor, for your
6 testimony.

7 I -- I was struck by the same thing that
8 Representative Mundy pointed out, that, you know,
9 you're looking towards us as being a body that's
10 going to make the kinds of changes necessary in the
11 medical field, and I -- I had the same feeling. I
12 believe that this should be part of any
13 relationship between a doctor and a patient.

14 And -- and it seems to me that we have
15 some gaps in a natural transition in our lives from
16 living to dying.

17 You know, when a person is in the state
18 that you have identified, just recently here, it
19 would seem to me the natural transition would be
20 then to take them from that nursing home and put
21 them into palliative care, hospice care.

22 What -- from your position, what would
23 need to happen in order to make that transition
24 smooth? And that transition, I would assume, would
25 be best decided by the -- the medical staff that's

1 attending to that patient.

2 DR. STRATON: These are great points.

3 And -- and I -- for many people who are living in
4 nursing homes, they've been living there for maybe
5 months or maybe years, and this becomes home. And
6 so in many ways people don't want to leave their
7 home. They want services brought in to them.

8 And so I think one interpretation is that
9 how do we make sure that people get all the
10 services they need in the home where they are?

11 And I absolutely agree with you. I think
12 physician education and education in the nursing
13 home communities about the benefits of palliative
14 care and hospice services is really critically
15 important so that we can -- so that those people
16 who are caring for the person in the nursing home
17 or -- or for family members who have taken care of
18 somebody in the home or physicians who are taking
19 care of people in the outpatient office or -- or in
20 the hospital, they know. They can see these
21 triggers, like, gosh, this is a person who can
22 benefit from those services. I need to call in
23 these services.

24 And the nursing home, in particular, I
25 think it's critically important that -- that we as

1 a medical community, as you're saying, educate
2 nursing homes about what are the -- what are the
3 triggers to call in hospice and palliative care
4 services that can -- that can benefit people who
5 are residing in a nursing home.

6 And for those people who are residing in
7 a nursing home who need care that they can't get in
8 the nursing home, to create smooth and simple
9 processes so they can move to a palliative care
10 setting.

11 Like we have an inpatient hospice unit
12 where people move from the nursing home, the
13 hospital, or the home to our inpatient -- our
14 inpatient hospice unit to get that level of care.

15 REPRESENTATIVE PASHINSKI: Are you
16 satisfied with the medical community's work in
17 trying to move towards your goal?

18 DR. STRATON: No. No.

19 REPRESENTATIVE PASHINSKI: So that's why
20 you've come to us?

21 DR. STRATON: Yes. Absolutely. But --
22 but --

23 REPRESENTATIVE PASHINSKI: It's a Catch
24 22 there.

25 DR. STRATON: But -- but also coming for

1 two reasons. One, I absolutely agree with you. We
2 have a lot more work to do in the medical
3 community, the nursing community, the social work
4 community, to educate all clinicians about what
5 services are available and how to talk with
6 patients about these services.

7 I also truly believe that it will be
8 helpful to non-medicalize this to make -- and this
9 is where I'm coming to you. I think something that
10 we can't do as a medical community is make
11 Pennsylvanians at large aware of the services that
12 are available to them, so that -- so that we think
13 of hospice and palliative care as something that
14 all Pennsylvanians should be asking -- like go to
15 your doctor and ask about this.

16 REPRESENTATIVE PASHINSKI: But that's
17 what I was suggesting, a transition from one phase
18 of your life into the next, it would be a natural
19 transition, you know, if -- if your medical
20 condition warranted it.

21 DR. STRATON: Yes.

22 REPRESENTATIVE PASHINSKI: No different
23 than when you get sick you go to the doctor or when
24 you get severely sick you have to go to the
25 hospital.

1 DR. STRATON: Correct.

2 REPRESENTATIVE PASHINSKI: And as you're
3 coming towards the end of life, then you -- you may
4 go into a nursing home and then into a hospice or
5 something of that nature.

6 Can I also ask you, do you have any
7 thoughts on, advance directives or living wills,
8 when that discussion should be initiated?

9 DR. STRATON: I do. And I actually did
10 quite a bit of research early in my career on -- on
11 advance directives and medical decision making.

12 I think advance directives comprise
13 several different types of documents. One is a
14 health care decision maker.

15 So -- so one as me designating my wife as
16 my health care decision maker if -- if I'm not able
17 to make decisions for myself, I think that's
18 something that everybody should do at any point in
19 life.

20 Because if they don't designate that, you
21 know, then -- then, you know, we have --
22 fortunately the Pennsylvania legislature passed a
23 provision that determines who the decision makers
24 are. Before that it was -- there was no
25 provision.

1 But -- but even that provision, you know,
2 may designate people who I might not want making
3 decisions for me.

4 And so -- so I think it's critically
5 important that everybody at every point in life
6 determines who -- whether they're terminally ill or
7 not -- who their decision maker should be.

8 Medical directives are things that say,
9 if I'm unable to make decisions for myself and I'm
10 terminally ill, I do or don't want dialysis, I do
11 or don't want CPR.

12 I -- the research shows that those are
13 very, very difficult decisions. And none of us can
14 really accurately predict -- predict a future
15 state.

16 I tell the medical students that -- about
17 this topic, that, you know, my wife and I, when we
18 were first engaged, we decided we were going to New
19 Zealand for our honeymoon. Eighteen months later
20 when we were married we went to Nova Scotia. You
21 know, we were only half a globe wrong. But it --
22 but we couldn't even predict that decision 18
23 months later. But, you know, there were things
24 like finances, time away from medical school, and
25 all that stuff that got in the way of going to New

1 Zealand.

2 And -- and the same way that I'm -- even
3 though I'm in this business, I don't know what I
4 want if I'm in a state 20 years from now or even a
5 year from now.

6 Medical directives are tough. I think
7 the most critically important thing is that every
8 single person designate and inform their clinicians
9 of who their decision maker is if they can't make
10 decisions for themselves, and then to have a
11 conversation with their decision maker.

12 I should have a conversation with my
13 wife. If I get hit, you know, by a car on my way
14 home that I do or do not want these things and then
15 she knows what decisions to make.

16 REPRESENTATIVE PASHINSKI: Thank you very
17 much, doctor.

18 DR. STRATON: Thank you.

19 REPRESENTATIVE PASHINSKI: Thank you,
20 Madam Chairman.

21 CHAIRMAN MUNDY: Representative
22 Samuelson.

23 REPRESENTATIVE SAMUELSON: You -- you
24 talked about medical reimburse -- Medicare
25 reimbursement. What are typical rates for hospice

1 care? How much does Medicare reimburse and are
2 there charges above and beyond Medicare which are
3 covered by either insurance or -- or family
4 members?

5 DR. STRATON: I think -- I think
6 Congress in 1982 did a great job of designing the
7 hospice Medicare benefits.

8 And I say that because all of us as we
9 die will probably have multiple illnesses, but we
10 enroll in hospice for just one of those and we
11 still continue our regular Medicare benefit for all
12 of our other illnesses.

13 So if I'm dying from heart failure and I
14 break my arm, I can still get my arm fixed. I can
15 still get curative treatment for everything else in
16 my body. I'm just receiving hospice for my heart
17 failure.

18 Medicare pays for home hospice about a
19 \$160 a day to the hospice program for everything
20 that the hospice provides, medicines, nurses,
21 doctors, social workers, beds, oxygen, everything.

22 And Medicaid and the private insurers
23 pretty much follow the hospice benefit. So
24 everybody pays about \$160 a day.

25 So for people who are short stays in a

1 hospice, three-day stay in a hospice, that's a
2 money losing venture for the hospice. You get
3 about \$500 to provide a ton of services. People
4 who stay in a hospice -- the break point is about
5 20 days on average.

6 And so -- so I think, you know, in
7 general the Medicare benefit pays well or -- you
8 know, nobody is making money on this, but Medi --
9 but -- it's -- it pays well.

10 Medicare currently is, I think, wisely
11 looking into paying more for the first few days and
12 the last few days of care when it's the most
13 expensive and paying less for the middle interval
14 of care where it's generally less expensive.

15 I think that's a much wiser way for
16 Medicare to pay for hospice services.

17 REPRESENTATIVE SAMUELSON: Do hospice
18 providers typically accept Medicare as full payment
19 or do they charge above and beyond?

20 DR. STRATON: Oh, thank you. Full
21 payment.

22 CHAIRMAN MUNDY: Representative Kula.

23 REPRESENTATIVE KULA: Thank you, Chairman
24 Mundy.

25 Doctor, we -- we've talked about -- and

1 you've enlightened me greatly on -- on hospice
2 care. But we all sitting here today and -- and
3 some of us are much, probably, closer to end of
4 life than some of us sitting here today. But
5 can --

6 REPRESENTATIVE WILLIAMS: Never know.

7 REPRESENTATIVE KULA: Myself included.

8 DR. STRATON: The representative pointed
9 no fingers.

10 REPRESENTATIVE KULA: I did not.

11 DR. STRATON: No.

12 REPRESENTATIVE KULA: Nor did I look at
13 anyone.

14 But as myself -- and I can tell you in --
15 in being a care giver, and most of the people here
16 today on the committee have heard me testify as far
17 as being a care giver for my mother, and the
18 hardest thing for me was she had no directive. I
19 pretty much had to say this is truly what I believe
20 my mother would want knowing my mother.

21 I -- I really never want my children to
22 have to make those decisions. I -- I mean I -- I
23 want to relieve them of that burden that I know I
24 had afterwards, did I do the right thing and is
25 this really what she would have wanted?

1 So can -- can anyone pretty much through
2 hospice care or is it just the -- the advance
3 directive route that -- that someone would take as
4 far as making sure that their wishes are known long
5 before it happens?

6 And in this day and age we really don't
7 know when that may be. So you're suggesting
8 advance directives and letting people know this.

9 Getting that word out, I -- I know most
10 people don't think about it. I know I did not
11 think about it until I was faced with that
12 situation as far as a power of attorney and -- and
13 things such as that.

14 But are there ways that we in the
15 legislature can help to educate people about what
16 needs to be done?

17 DR. STRATON: I believe there are, yes.
18 The -- I think, as we described, picking a --
19 picking someone who will be your decision maker,
20 writing that down, giving that information to your
21 physicians. Telling that decision maker what you
22 would want.

23 Even just in general terms. You know
24 what, if I'm hooked up to a machines and I'm never
25 going to get off those machines, I don't want

1 that. Please stop those machines.

2 That's -- my brother instructed us, I
3 don't want to be a vegetable. This is 20 years
4 ago. And so that was enough for us to know that,
5 you know, if there were machines that he was going
6 to be hooked up to, that he didn't want to, that we
7 said, no, he does not want that.

8 And I think also clearly picking who that
9 decision maker is. I have many people who say, you
10 know what? I can't burden my kids with this.

11 So they choose a neighbor or -- or people
12 will say, you know what? My kids, they're going to
13 ignore what I say. So I'm going to chose, you
14 know, this person who really doesn't love me as
15 much as my kids do because they're going to do what
16 I tell them to do. And I've had people who said
17 that and it works out well.

18 And advance directives, I think, are
19 critically important. Even though I've said, you
20 know, I couldn't figure out -- you know, I was a
21 poor predictor of where we wanted to honeymoon and
22 I'm probably an equally poor predictor of what I
23 don't want specifically in the future, if I'm brain
24 dead, if I'm Karen Ann Quinlan, there are things
25 that I don't want.

1 And -- and that's what those medical
2 directives are critically important for. I can
3 check all those boxes, give those to my physician,
4 give them to my kids, that way when my kids -- when
5 I'm in that condition and my kids are asked,
6 instead of saying, gosh, I don't know or I think or
7 my kids fighting, no, he wanted that, no, he
8 didn't, they can just go pull this out and say,
9 look. Dad wrote it down.

10 And so many family members, so many kids
11 say, thank God mom wrote this down because now it's
12 easy for me.

13 There's a great advance directive
14 document called Five Wishes that is -- I'm blanking
15 on who developed it. It's called Five Wishes.
16 It's easily, you know, visible through Google.

17 One of the -- one of the problems with
18 many advance directives is they're written in
19 medical language. If I am in such and such a
20 condition, I do or do not want these treatments
21 that I don't have a clue what they are. They're
22 written in medical language, not people language.

23 Five Wishes is written in medical -- in
24 people language. If I am dying, I do want this
25 music played. I do want to be massaged. I do not

1 want these interventions. And it explains what the
2 interventions are. Five Wishes is a great
3 document.

4 Pennsylvania is one of the several states
5 where that is a legal advance directive and I think
6 that -- one thing that we can do as a medical
7 community and as a state is to promote that
8 document because it's very user friendly.

9 REPRESENTATIVE KULA: Okay. And -- and
10 do you find that, you know, are there times that
11 advance directives are -- are questioned by family
12 members that say this advance directive was done
13 two years ago, three years ago, and as you talked
14 about your honeymoon, and -- and maybe, you know,
15 someone -- you know, one family member saying,
16 well, I don't think she was really thinking
17 clearly, this isn't really what she would want,
18 and -- I mean do you see those types of conflicts?

19 DR. STRATON: Every day. Every day. And
20 I think my job as a physician is really counseling
21 families in that situation.

22 And -- and I think to many of your
23 points, I think one of the things that we need to
24 educate the medical community about is that this
25 document, it's a living, breathing document, and

1 that our job is to help work with families to say,
2 what is it that dad -- what do we think dad was
3 saying at that time? We -- we know what he wrote
4 down. He may or may not have understood what these
5 check boxes meant. But, you know, this is the
6 condition dad is in. What would he -- if he could
7 speak right now, what would he tell us?

8 And that's the purpose of the document,
9 is that when somebody can't speak any longer, what
10 would they -- what would they say if they could
11 tell us?

12 And I think that's something that we as a
13 medical community don't do a good job of. We -- we
14 walk in. We have a quick conversation. We say,
15 look, that's what dad said. You know, tough
16 beans.

17 But -- but, you know, I think that -- you
18 know, I think of when I bought a house, my real
19 estate counselor was, you know, more of a financial
20 counselor, marriage counselor, and all these other
21 roles.

22 And I think, you know, this is an equally
23 big decision to buying a house, and we need to
24 counsel family members through it by help -- by --
25 by just saying, this is the condition that dad is

1 in. If dad could talk now, what would he want?

2 What would he say?

3 And regardless of -- and use the document
4 as a guide but not a rule book. Thank you.

5 REPRESENTATIVE KULA: Thank you very
6 much.

7 Thank you, Chairman.

8 CHAIRMAN MUNDY: Representative Quinn.

9 REPRESENTATIVE QUINN: Thank you, Madam
10 Chair.

11 And thank you, doctor, for being here.

12 You've said through your testimony at one
13 point that people can enroll sooner?

14 DR. STRATON: Yes.

15 REPRESENTATIVE QUINN: But I'm under the
16 impression from what I know of hospice that
17 typically someone who's not self-referring, there's
18 typically -- they're that ill that they're not --
19 it's not a cognizant decision on the part of the
20 patient. Am I correct?

21 DR. STRATON: You are correct.

22 REPRESENTATIVE QUINN: Okay. So then you
23 mentioned about your friend who came to you with
24 the breast cancer and said, well, you should have
25 -- you said, she should have, could have been here,

1 like, four years ago, for palliative services.

2 And you used the word services
3 throughout, but I -- I've yet to hear a menu other
4 than it's not morphine. I mean could you tell
5 me -- I mean at four years prior, she's not going
6 to obviously be laying in a bed in four years.

7 DR. STRATON: Right.

8 REPRESENTATIVE QUINN: Like what type of
9 services would you -- would be included in a
10 typical care like that? Are you counseling her
11 that could be contrary to what the doctor is
12 saying, let's try this? Because at one point for
13 her to self-refer I think there's -- she's giving
14 up hope that she can beat the darn cancer.

15 DR. STRATON: Thank you very much for
16 bringing that up. One of the big differences
17 between palliative care services and hospice
18 services, hospice is an insurance-defined benefit.
19 It provides a huge package of services, home health
20 aides, nurses, nurse -- home nursing visits, free
21 medications for symptom management, volunteers,
22 physicians, social workers, a huge and relatively
23 expensive package of services.

24 And so it's -- to make sure that Medicare
25 doesn't go broke, it's -- it's limited who can

1 enroll. So it's limited to people who have a
2 prognosis of six months or less, they're likely to
3 die in six months or less, and to people who are no
4 longer pursuing curative treatment for that
5 illness.

6 So my friend four years ago would not
7 qualify for hospice services because she's still
8 pursuing curative treatment.

9 That's why palliative care services can
10 be very beneficial, hand in hand with curative
11 services. And -- and those palliative care
12 services are tougher to pin down because, as I
13 said, in our three Penn hospitals they're different
14 in the three hospitals. And so they're different
15 across the Commonwealth.

16 Palliative care services can be -- in
17 general are really aggressive symptom management.

18 Thinking of my friend in general, she
19 was naus -- I'm sorry. It's after breakfast. She
20 was nauseous from the chemotherapies that she was
21 receiving. She should -- she should be seeing a
22 symptom specialist in addition to the oncologist to
23 aggressively manage her nausea while she's getting
24 the chemotherapy.

25 I don't think people should be forced

1 into a choice of curative treatment or feeling
2 good. They should get both. And -- and that's
3 where palliative care services over the last four
4 years, in combination with the chemotherapy, she --
5 could have really benefited her.

6 REPRESENTATIVE QUINN: I could only
7 imagine that if there was an oncologist sitting
8 here right now he would say, wait a minute. When
9 I'm treating someone, I'm also very cognizant of
10 their -- their vomiting and can't do much about the
11 hair loss, but that's -- you know, I have friends
12 through it. So it seems like there's almost
13 another leg that you're putting on that stool of
14 total treatment.

15 DR. STRATON: Yes. And -- and is there
16 another leg I'm putting on the stool? Yes. Yes.

17 And I think there are -- there are many
18 oncologists who are outstanding at managing
19 symptoms. There are many oncologists who are not
20 outstanding at it. And I think everybody should
21 have access to outstanding symptom management.

22 And so I think for many oncologists,
23 having another leg on the stool, having another
24 specialist involved, I think would be very, very
25 helpful.

1 Does everybody need that? No. Do many
2 people need that? Yes.

3 REPRESENTATIVE QUINN: Thank you.

4 CHAIRMAN MUNDY: Representative Gingrich.

5 REPRESENTATIVE GINGRICH: Thank you,
6 Madam Chairman.

7 Actually I think I'm going to ensure your
8 services now. I like your style and Deb has me
9 very scared that I might be next. I -- I truly
10 like your perspective on the -- on the palliative
11 care piece.

12 What I wanted to do was -- was highlight
13 more specifically in a hospice category something
14 you talked about earlier in the challenges that our
15 nursing homes face, almost on a weekly, sometimes a
16 daily basis, they have to help make these decisions
17 with and for families.

18 In my prior industry life I worked in
19 health care and aging, and I worked in a CCRC where
20 we did all that.

21 DR. STRATON: Yep.

22 REPRESENTATIVE GINGRICH: Very large,
23 very up scaled, thoughtful mission-based
24 operation.

25 And one of the things that is burned into

1 my mind was an experience that I not only observed
2 but had to be part of and it was -- it was a
3 patient who had transitioned through a vital life
4 and residential living there to the nursing home,
5 24/7 skilled and was at the end of her life. Knew
6 it, was cognizant.

7 It happened to be a cancer-related thing
8 that it was clear what was happening to her. She
9 made a conscious decision that the battle was over
10 for her and she was at peace with that and wanted
11 to proceed with that.

12 It became a conflict with the mission of
13 the community to allow her to say -- she -- her
14 mistake may have been in verbalizing that, in
15 saying I recognize this and I want to plan for my
16 end with dignity.

17 And she looked for all these
18 opportunities to -- for -- in one aspect simply
19 stop eating.

20 Well, the nursing home found great
21 conflict in that. And this was several years ago,
22 and I'm -- I'm hoping that we've -- we've
23 accommodated some of that a little better than we
24 were forced to do at that time.

25 But what happened to this woman who was

1 being cared for well, but her needs had changed at
2 the end of life, we weren't -- we made an
3 administration -- administrative decision not to
4 allow her to do that, and she left the facility and
5 went to her daughter's home and we made -- they
6 made all that possible for her at home and she was
7 able to end her life with the dignity and the plan
8 that she had for herself.

9 I don't know that legislatively what
10 we -- we as legislators are very sympathetic and
11 understanding of this, but a regulatory system it
12 would seem, looking straight at Secretary Hall,
13 that we need to -- we need to talk about what --
14 what we can do to improve the opportunities for
15 both facilities providing -- I'm talking now
16 nursing home --

17 DR. STRATON: Uh-huh.

18 REPRESENTATIVE GINGRICH: And there's a
19 lot of dignity in staying home and making these
20 arrangements. There's no question about it. But a
21 lot of people are in -- are in facilities.

22 Have you seen that in your time in the
23 field? Have you seen that improve, not improve?
24 Can we help with that regulatory process that is so
25 important but so tightly binding to our nursing

1 homes?

2 DR. STRATON: I think there are ways that
3 we can improve that process from a regulatory
4 standpoint for nursing homes. Again, Joan Teno is
5 in -- works in Brown University and through her
6 work Rhode Island has made great strides in
7 accommodating the needs of people who are dying in
8 nursing homes.

9 The state of Oregon has also done a great
10 job of being very proactive in adjusting the
11 nursing home regulations to accommodate for people
12 who are dying in nursing homes.

13 And -- and I'm very sympathetic to
14 nursing homes and the challenges they face because
15 they -- they're -- there are these two discordant
16 populations. The large majority of people who are
17 there for restorative care.

18 But there are many, many people who are
19 going to die there and -- and -- and as we're
20 dying, all of our organs slow down and if we put
21 food into a stomach that's slowing down, it just
22 sits there and makes people nauseous. It's kind of
23 like post Thanksgiving, you know, on a regular
24 basis. It's not comfortable.

25 And so -- so I think -- I think that

1 there are ways, following the models of Rhode
2 Island, Oregon, and other states that have really
3 pursued this very aggressive that we can follow up
4 on -- on some of the regulatory changes that
5 they've made to accommodate the needs of people who
6 are dying in nursing homes, to help nursing home
7 administrators feel that we are not going to be
8 punished for providing great end-of-life care.

9 I think right now many nursing homes and,
10 Chairwoman Mundy, as you also said, you know, in
11 Florida that many nursing home administrators feel
12 like we're going to face a choice, either we
13 provide great end-of-life care for this patient and
14 get deficiencies because of it or we don't get
15 deficiencies and we don't really meet the needs of
16 this patient.

17 So I think that there is from a statewide
18 basis opportunities to really look thoughtfully at
19 the current regulations and see if there are ways
20 that they can be tweaked.

21 REPRESENTATIVE GINGRICH: I want to thank
22 the chairman for -- and those who organized this
23 discussion today because I think it's critical
24 that -- that we bring this to our attention and
25 determine what we can do to help, to help move it

1 along, but ultimately to improve -- improve the
2 circumstances.

3 And as Deb said, you know, we're just
4 around the corner.

5 DR. STRATON: Thank you.

6 CHAIRMAN MUNDY: Representative Brown.

7 REPRESENTATIVE BROWN: Good morning.

8 DR. STRATON: Good morning.

9 REPRESENTATIVE BROWN: And thank you for
10 your testimony.

11 I had an experience where I have
12 requested the services of hospice care. Many times
13 I talk about my relatives that I take care of. And
14 I have a 90 -- well, she was 94 at the time, and
15 she totally fit the requirements.

16 The doctor gave her six months, and she
17 wasn't eating, she wasn't thriving, and there was
18 no curative medication for her.

19 And we brought in the hospice care, and
20 she greatly appreciated it, and you'd be surprised
21 how much she appreciated it. She came out of the
22 depression, and she's still here two years later
23 after the hospice care.

24 And I'd like to note, do you have any
25 statistics on how many of the patients who receive

1 hospice care actually do start to thrive and not
2 expire?

3 DR. STRATON: We -- there's a -- a
4 colleague of mine, Dave Casarett, who is a
5 nationally known researcher, who has done work
6 on -- on what we informally call hospice graduates,
7 and it's about five -- five to ten percent of
8 hospice enrollees across the country who -- who
9 thrive with the hospice services.

10 And I think it's really a testament to
11 really the -- the impressive amount of services
12 that hospice provides and how well people can do
13 when they're receiving home health aid visits, home
14 nursing visits, social work visits, all this
15 attention that -- that can really help turn around
16 what looked like a dying process.

17 And so it's -- it's about five to -- five
18 to ten percent of the population across the nation
19 of hospice enrollees who -- who graduate from
20 hospice.

21 REPRESENTATIVE BROWN: It's good to hear
22 that you have hospice graduates. I love that
23 term.

24 DR. STRATON: Yes.

25 REPRESENTATIVE BROWN: And I just wanted

1 to add, with my aunt at the age of 94, I think that
2 there are many elderly folks when they hit 90 they
3 think it's over, and a lot of people don't realize
4 that with the medical care we have and the quality
5 of life that we have that there are more people
6 thriving to over a hundred. And individuals just
7 are not accepting that until they're faced with
8 it.

9 She's now 96.

10 DR. STRATON: Uh-huh.

11 REPRESENTATIVE BROWN: And she's starting
12 to believe that possibly she could live beyond a
13 hundred.

14 DR. STRATON: Uh-huh.

15 REPRESENTATIVE BROWN: And we really
16 changed her quality of life and mental status
17 because of the hospice care.

18 DR. STRATON: That is so great to hear.

19 You know, we had a 102nd birthday on our
20 hospice unit a couple months ago, and it was -- it
21 was awesome. It was so fun.

22 We also had a college graduation a month
23 before that. It was really kind of both ends of
24 the spectrum. It's -- it's been a lot of fun.

25 I know it's weird to say hospice is a lot

1 of fun. Sorry.

2 CHAIRMAN MUNDY: That's quite all right.
3 Representative Kortz.

4 REPRESENTATIVE KORTZ: Thank you,
5 Chairwoman Mundy.

6 Thank you, Dr. Straton, for your
7 information today.

8 I just wanted to key upon what
9 Representative Gingrich had mentioned. It's not an
10 isolated incident where people won't eat.

11 I went through that with my uncle, and
12 this was a guy who fought in World War II in the
13 Marines and went through all the way with the
14 island hoppings, all that carnage.

15 But at the end of his life, he told me
16 one day, he said, I can't taste anything.

17 DR. STRATON: Uh-huh.

18 REPRESENTATIVE KORTZ: He said, Young
19 Bill, he said, it just -- it just -- there's no
20 taste to it. It tastes like cardboard. And
21 obviously his body was breaking down. He just
22 refused to eat.

23 He just said it was -- it's not an
24 isolated incident. And there's nothing they could
25 do. So I just wanted to make a comment.

1 DR. STRATON: Thank you. And I think
2 along those lines, there are -- one of the
3 challenges is separating, you know, which people
4 have kind of made a decision that they're ready to
5 die because they're depressed and which people have
6 made a decision that, you know, it's time to die
7 because they've really hit the end of the road and
8 life -- there's no way that life can have the
9 quality or meaning that -- that brings, you know,
10 them satisfaction.

11 And I think it's really important that
12 people know that they have -- they do have control
13 over this. That -- that people who are dying and
14 don't want that dying process prolonged can choose
15 to stop eating.

16 They can choose -- you know, I mean none
17 of us can commit suicide. None of us can commit
18 euthanasia. But people can decide to stop
19 life-continuing or -- or life-prolonging
20 interventions of a whole variety, from mechanical
21 ventilation to tube feeding.

22 And -- and that all these interventions
23 that are life prolonging are -- you know, it's
24 totally permissible to stop so that people can die
25 naturally.

1 So thank you very much.

2 CHAIRMAN MUNDY: Dr. Straton, we thank
3 you so much for being here this morning and sharing
4 all this valuable information and your experiences
5 with us.

6 Thank you.

7 DR. STRATON: Thank you. It's been a
8 great honor. Thank you very much.

9 CHAIRMAN MUNDY: Now, ladies and
10 gentlemen, we're now 35 minutes late, but I think
11 that was well worth the extra time, that dialogue
12 with Dr. Straton.

13 Next we're going to hear from the Rendell
14 Administration, our own Secretary of the Department
15 of Aging, Secretary John Michael Hall. And Ann
16 Torregrossa, Director of the Governor's Office of
17 Health Care Reform.

18 SECRETARY HALL: Good morning.

19 CHAIRMAN MUNDY: You can begin whenever
20 you're ready.

21 SECRETARY HALL: Thank you.

22 DIRECTOR TORREGROSSA: Good morning.

23 SECRETARY HALL: I -- my name is John
24 Michael Hall. I'm the Secretary of Aging. It's
25 nice to be back with the committee. Thank you for

1 inviting me to come and talk about this.

2 I'll talk louder.

3 This is an issue that, like Dr. Straton,
4 I worked on early in my career. It's been a
5 personal and professional passion for more than two
6 decades.

7 And, frankly, I can't imagine -- and I
8 say this in all sincerity in listening to
9 Dr. Straton's testimony -- I can't imagine anybody
10 better to follow than -- than him in terms of
11 laying out the key issues that we still deal with
12 in this area.

13 You have copies of prepared testimony
14 that my staff worked on, and let me first say that
15 I think they did a wonderful job. And then let me
16 say next that I'm not going to rely on it at all in
17 my comments.

18 I'm going to -- I think it covers some of
19 the history and some of the work that's going on
20 now.

21 And I know that Anne is going to want to
22 talk about some of the work that the Governor's
23 Office of Health Care Reform has been doing on this
24 issue and, most recently, work that they've done
25 with Allegheny County and the -- and the Area

1 Agency on Aging out there. So I will -- I'll leave
2 that to her.

3 I -- I noted again today that whenever we
4 talk about this subject, whether it's Dr. Straton
5 himself or whether it's the members of the
6 committee, it's almost impossible to talk about
7 this subject without relating to it on very
8 personal terms.

9 Everybody has a story. Everybody has an
10 experience that they've gone through. And I'm not
11 immune to that either. So I'm going to share with
12 you some of my history with this as a way of
13 illustrating what I think doesn't work as well as
14 the things I think that we can do.

15 And I want to make a point also of coming
16 back and talking to some of the issues around how
17 we approach death in nursing homes and how we
18 interface with the hospice program before I finish.

19 Back in the mid '80s I started working
20 with the Vermont Ethics Network to work on some of
21 the earliest advance directives. Working to put
22 things like living wills into people's hands.

23 I was the lead drafter of one of the
24 earliest durable powers of attorney for health care
25 and then lobbied the legislature to pass it.

1 And what was significant about that event
2 was not that the legislation itself passed. It was
3 more significant that it triggered a earnest
4 discourse within the state about this whole
5 question of end of life.

6 It resulted in meetings around the state
7 over the course of many years, in communities and
8 town meetings, trainings with doctors and lawyers,
9 meetings that I -- I spent hundreds and hundreds of
10 hours over the years going to hospitals on
11 Wednesday nights or on Tuesdays at lunchtime,
12 meeting with doctors when they were doing their
13 staff meetings.

14 We held trainings where nurse
15 practitioners and folks from nursing homes and
16 folks from hospitals would come in and we would
17 talk about the bio and medical and legal and
18 ethical issues of how this works, what the
19 documents are and how you help people go through
20 them and what they mean and how you honor them and
21 how you deal with conflicts that arise.

22 And I will readily admit that in those
23 days when I was more naive and bright eyed than I
24 probably am today, I thought that these issues,
25 particularly as somebody who writes statute, you

1 tend to think, well, it's the law, it's clear,
2 they're clear lines, and things are black and
3 white.

4 And I look back at the trainings and the
5 conversations we had where a doctor would get up
6 and ask, how should we handle this? Or I would
7 stand in front of a group of 300 people and say,
8 this is how you react if you have an instruction
9 from a surrogate under power of attorney.

10 And what you -- what you figure out over
11 time, or at least I did, is that this is an area
12 where things are not and cannot be black and
13 white. Where they are almost inescapably gray.

14 And you come to these situations and
15 families in a very situational way trying to figure
16 out what's the best thing that you can do. And
17 even if you have an advance directive, you find
18 that you're still trying to find your way towards
19 the right decision.

20 About ten years after I started working
21 in this area and doing all those trainings and
22 writing booklets and working with the legislature,
23 my mother was diagnosed with advanced liver cancer
24 on Mother's Day in 1996.

25 She was reported feeling badly on that

1 Sunday and was -- we took -- my sisters took her to
2 the hospital. And what happened was a intensive,
3 aggressive course of treatment for the liver cancer
4 that took her through the spring and into the
5 summer and into the fall.

6 And I by that time was living in New
7 England, but I visited her several times during the
8 course of that treatment. And then one day in
9 early October I got a phone call from my sister
10 that mom was not going to last long and that I
11 needed to get on the next plane to Illinois.

12 So I drove the three hours to Boston
13 Logan Airport faster than I have ever driven them
14 before or since and got on a plane and was in her
15 hospital room in midafternoon.

16 Shortly -- within half an hour after I
17 got there, her treatment team, including the lead
18 oncologist, came into the room on normal rounds and
19 started describing for her the steps they were
20 going to take to start trying to make her more
21 comfortable. And during the course of that
22 discussion, it struck my mother that what they were
23 talking about is that she was going to die.

24 Over the course of the summer, remember,
25 she had been going to chemotherapy on a weekly

1 basis, would call me up every week and tell me what
2 her white blood count was, tell me what her
3 progress was. But the truth is that during those
4 six months she wasn't, in fact, progressing. The
5 cancer was metastasizing and she was getting weaker
6 and weaker.

7 But that was a conversation that never
8 occurred between her and the oncologist and the
9 doctors until that day in early October when he
10 started describing the fact that they weren't going
11 to do any further treatment and that they were
12 going to start preparing her to be comfortable.

13 Remember, I had flown in because my
14 sister had said that she was probably not going to
15 last the day. And my mother said, you're telling
16 me that I -- that you can't cure me. You're
17 telling me that I'm going to die. And the doctor
18 said, yes.

19 And let me just tell you something about
20 my mother. My mother was a very strong willed,
21 very tough person. She was not the kind of person
22 who you made angry. And -- and all of my brothers
23 and sisters will attest to that.

24 That really made her angry. And
25 obviously what was wrong with what happened on that

1 day is that conversation should have happened
2 months before. The type of cancer they were
3 treating was not novel or new. The course of the
4 disease was not a surprise.

5 And my mother, by sheer force of will,
6 lived for another two weeks. I want to emphasis,
7 she lived, despite all the medical evidence that
8 said she should have died that day, for two more
9 weeks because she was mad. She refused to sleep.

10 Going back to something that Dr. Straton
11 said, she refused to let the priest into the room
12 because the priest coming into the room was the
13 signal that that was the end.

14 She refused to die. And she put it off
15 for two solid weeks before death finally overcame
16 her.

17 Now, the tragedy in that case is that a
18 lot of damage, I think, was done to her -- to her
19 and to the family members by the way that was
20 approached. My mother spent the last two weeks of
21 life fighting to stay alive when what she should
22 have been doing was getting ready to die.

23 She spent that -- those last two weeks,
24 and indeed the spring and the summer and the fall,
25 not coming to terms with the fact that she was

1 going to be leaving this world. She came -- she
2 spent the time every week optimistically looking
3 forward to her recovery instead of putting her
4 affairs in order.

5 She had seven children. And the
6 children, in another example of the difference
7 between theory and reality, were all over the map.
8 There were -- there was one sibling who was --
9 wanted to know why we weren't increasing the
10 morphine drip and a couple of brothers who were in
11 complete denial that she was dying at all.

12 One of the family members had arranged to
13 have her sign a power of attorney for health care
14 designating my dad as the surrogate to make
15 decisions, which, to be perfectly honest, was just
16 about the absolute worst choice of anybody to be a
17 surrogate that could have been made.

18 My dad was a wreck, and he was not
19 capable of making a single coherent decision about
20 how to handle her death, not to mention the fact
21 that he was afraid of her.

22 And so those last weeks were terrible to
23 get through. How do you span -- how do you span
24 the differences between the siblings? How do you
25 give the doctors instructions about what to do?

1 How do you talk to mom about the fact that she is
2 leaving?

3 And -- and as a result, when she finally
4 died on the afternoon of October 15th, neither she
5 nor anybody in that family was prepared for the
6 fact -- for her death.

7 I think when we talked palliative care
8 and when we talked about the difference between
9 comfort care and the measures that can be taken to
10 help people deal with terminal disease, what, I
11 think, sometimes gets left out of the discussion --
12 and I'm not saying this in the sense to be critical
13 of the conversation we've had this morning or
14 Dr. Straton's comments at all -- is, as important
15 as focus on good pain management is and as
16 important as palliative care should be in terms of
17 our approach to how we work with people who have
18 terminal disease, I think we also need to recognize
19 that a key element of hospice, for instance, and a
20 key element of our responsibility to patients, is
21 to recognize that there is a nonmedical aspect to
22 dying; that there is the psychological aspect; that
23 there is some coming to terms with our own death
24 and helping people. All of us are reluctant.

25 As Dr. Straton said, who among us brings

1 this up on our own? Who of us wants to even
2 contemplate that we're going to die?

3 I think that from a public policy
4 perspective one of the things that we need to do is
5 making sure that the conversation happens,
6 recognizing that we're probably not going to
7 initiate it ourselves.

8 A number of years ago Congress passed the
9 Danforth Patients Self-Determination Act which
10 required that every individual who is admitted to
11 care in a nursing home or hospital or at home
12 health care that receives funds from the federal
13 government is required to be provided with
14 information about advance directives.

15 But I think obviously that this is more
16 than handing people a packet on admission. It's
17 about how do you ensure that there's a culture that
18 puts this on the table, that says, let's talk about
19 this.

20 Standing in the room when my mother was
21 dying in those two weeks was my uncle John, her
22 closest sibling, and he had a chance to -- and he
23 and I talked, both of us attorneys, about what we
24 were seeing and how we were going to handle the
25 ethical issues and the conflicts between the

1 brothers and sisters.

2 He was diagnosed earlier this year
3 with -- with an advanced form of lung cancer.

4 The -- there are two key differences in
5 John's experience versus my mother's. The first is
6 that he made a decision to not undergo aggressive
7 treatment to combat the disease.

8 The final ten months of his life were
9 spent at home with his family, having dinner on
10 Wednesday nights with his granddaughter, going out
11 for walks with the dog, watching Judge Judy in the
12 afternoon and doing the crossword puzzles at lunch
13 with his aunt -- with his wife, and trying to
14 maintain as normal a life as he could with as much
15 quality as he could in those months.

16 And my aunt and I talked a lot in the
17 days after his death, and one of the things that we
18 contrasted is how different those ten months would
19 have been if he had agreed to start -- undergo
20 chemotherapy. Not the least of which is it
21 wouldn't have changed the course of the disease and
22 it wouldn't have changed the date of his death in
23 any meaningful way.

24 But it would have changed what his
25 relationship was with his family and what those --

1 and his ability to get ready for his own death.

2 The other thing that was notable is that
3 he was treated at a hospital in the suburbs of
4 St. Louis that had a very progressive policy on
5 ensuring that every individual who was being
6 treated for terminal disease in -- on their
7 treatment team included not only the oncologists
8 and the physicians who were managing their care,
9 but also on that treatment team included palliative
10 care physicians and -- and -- and -- and
11 counselors.

12 And so, even when he was admitted to the
13 hospital a couple weeks before he died, one of the
14 very first contacts that he had was with members of
15 the palliative care team to talk about how -- how
16 the next -- what alternatives he had and how he
17 could shape what the next weeks should look like.

18 In the work that we did in the past when
19 I was working with the Ethics Network, one of the
20 things that we did was work with hospitals, for
21 instance, to encourage hospital boards to put
22 into -- to make changes in their bylaws and
23 operating principles, incorporating the concept of
24 palliative care in their standard operating
25 protocols so that every physician who was on staff

1 at that hospital would do the kind of thing that I
2 was talking about -- that I was describing happened
3 at the Sisters of Mercy Hospital a few weeks ago
4 with my uncle.

5 I do think that from a public policy
6 perspective one of the things that we can do and
7 one of the things we need to do is institutionalize
8 the conversation. Not because we're trying to push
9 people in a certain discussion. This is about
10 choice.

11 But choice has to be about making sure
12 that they have full information and neglecting to
13 have a conversation with someone about the
14 prospects for recovery, the effect it's likely to
15 have on their quality of life, the degree to which
16 this will change their outcomes, neglecting to
17 include that early on is neglecting to give them
18 the kind of information that they need to have to
19 decide how they want to handle this.

20 It's pretty hard for people who are in my
21 mother's situation to come to terms with their own
22 mortality if they're being -- if they're not told
23 that they're going to die, and I think that is
24 missing today from a large number of conversations
25 and interactions that people have.

1 Let me talk quickly about some other
2 public -- public policy work that we're doing.

3 I'm -- I'm glad actually that the
4 committee spent so much time talking with
5 Dr. Straton about -- about the issue of nursing
6 homes.

7 You know, today nursing homes by and
8 large have two types of patients in them as the
9 doctor said, people who are in there for short-term
10 rehabilitation and people who are at the end of
11 life.

12 People who have stayed at home typically
13 for as long as they possibly can and then because
14 of the complexity of their illness or the fact that
15 their needs have taxed their family's capacity to
16 keep them independent any longer, they go into
17 nursing homes for the last few weeks.

18 So in numbers that are quite high today,
19 as he said, people die in nursing homes, but they
20 die in an environment that is conflicted about --
21 about that.

22 Back in 1987 Congress passed the Nursing
23 Home Reform Act called OBRA 87 which put in place a
24 very strong, quality structure for making sure that
25 people had initial and regular assessments of their

1 condition, that they had comprehensive care
2 planning which was regularly updated.

3 And a key aspect of the Nursing Home
4 Reform Act was the requirement that nursing homes
5 maintain and help -- nursing homes do everything
6 they can to help patients attain and maintain the
7 highest practicable level of physical, social, and
8 psychosocial functioning.

9 The problem with that standard -- well,
10 let me say this. In 1987 the people who were in
11 nursing homes, the cross-section of who we were
12 serving there, looks much -- looked much different
13 than it does today 22 years later. And I think
14 Representative Gingrich can attest to that.

15 The -- imposing the highest practicable
16 level of functioning standard did worlds of good
17 for improving the quality of care in nursing homes
18 for 1987.

19 And none of us who have worked in this
20 field and none of us from the nursing industry
21 would ever want to go back to what it was like
22 before OBRA 87 was passed.

23 But I think what we now know is that that
24 standard care of care is not particularly
25 compatible for people who are dying. That we are

1 doing all the things that Dr. Straton talked about
2 in order to assure that we don't get a deficiency
3 when the nurse surveyors come and struggling with
4 the fact that what people really want to do is they
5 want to be comfortable, they want to be left alone,
6 and they want to die in peace.

7 And so there is work that has started in
8 other states on making changes to the culture of
9 nursing homes and the regulatory environment.
10 We've started to have discussions here in my
11 department about doing that as well.

12 And in the coming weeks my plan is to
13 bring together folks from the Department of Health
14 who do the surveys in nursing homes, as well as
15 folks from the nursing home industry, to talk about
16 how we change the culture and the regulatory
17 standards and the standard of practice in nursing
18 homes so that we recognize the reality of the
19 people who receive services there today.

20 In the area of hospice and Medicaid, one
21 of the real challenges we have had historically is
22 that we have two programs, Medicare and Medicaid,
23 and that -- that despite the fact they're
24 administered by the same federal agency, can't
25 figure how to get along with each other all that

1 well.

2 The -- even within our hospice benefit
3 paid for by Medicaid, programs for -- that are
4 the -- the program that we have for providing
5 hospice services to people who have terminal
6 illness has been historically all but incompatible
7 with the services that we provide under the aging
8 waiver for helping people living independently in
9 the community as they age. So much so that
10 patients have been forced in many cases to choose
11 one or the other.

12 The benefits in the aging waiver and the
13 benefits in hospice are not the same. They have
14 great strengths in some areas, but they don't do
15 everything.

16 And too often people are forced to decide
17 am I going to take the hospice benefit and go
18 without the supports I could get under the aging
19 waiver that help me -- that -- that support home
20 and community-based services or am I going to take
21 the aging waiver and go out -- go without the
22 benefits of hospice?

23 So we're in the process right now of
24 changing that policy. We recently issued a draft
25 policy statement that -- sent it out to

1 stakeholders for their feedback that will harmonize
2 hospice and home and community-based waiver
3 service, wrap them around each other, and allow
4 individuals who are receiving long-term care to
5 receive -- take -- get the benefits from both at
6 the same time, not have to choose one or the
7 other.

8 And we hope to have comments back from
9 home health agencies, area agencies on aging and
10 other stakeholders in the near future and be able
11 to finalize that policy so that we administer those
12 programs in a way that meets the needs of the
13 individuals rather than being focused on the
14 programmatic rules.

15 The -- I think the -- the last thing that
16 I will say is that from a larger public policy
17 perspective there continues to be a challenge in
18 terms of the -- the degree to which this is part of
19 the education that -- that happens in the medical
20 community.

21 End-of-life care, palliative care is, in
22 most cases, not part of the core curriculum in
23 medical school, and too many physicians come out of
24 school with this not being a central part of their
25 training or their consciousness.

1 There are a growing number of physicians
2 who have a focus and a passion for palliative care
3 and for hospice, like Dr. Straton, and I have had
4 the honor of working with many of them over the
5 years.

6 But this needs to be the -- the
7 conversations that are happening, often happen in
8 the office, in your home town, with your primary
9 care physician when the results of the x-rays come
10 back, and that's the place where the conversation
11 and the choice-making often needs to start. And we
12 need to train doctors. We do a better job today
13 than we did before.

14 When we were doing the early work in this
15 20 years ago, the dynamic of patients and doctors
16 was much different. We didn't think that patients
17 had the right to question a doctor, or to ask
18 questions or to say I want this. We were supposed
19 to listen to what physicians were telling us --
20 told us.

21 We've come a long way in the ensuing two
22 decades and some of the work that's happened in
23 legislation and the -- the national discussion
24 about this has advanced that.

25 But I think we have more work to do.

1 We -- I think that we do need to do a better job of
2 training as well.

3 So let me -- let me leave it there and
4 turn it over to Anne.

5 DIRECTOR TORREGROSSA: Good morning.

6 CHAIRMAN MUNDY: Good morning.

7 DIRECTOR TORREGROSSA: It's not H1N1.

8 That's the good news. I have these -- these
9 grandchildren who are like little petri dishes.
10 They go out in the community and they gather all
11 the germs and they bring them back to me when I
12 babysit.

13 So pardon me for my gravelly voice.

14 I want to focus on an area not covered by
15 the end-of-life task force report, and that is the
16 large geographic and hospital variations and the
17 amount and cost of care Pennsylvania patients
18 receive at the end of life.

19 The research, more than 20 years, that
20 Dartmouth College has done has conclusively shown
21 that some hospitals spend much, much more on end of
22 life than others.

23 And so this is follow the money, and this
24 issue is -- is an important one that we can't miss
25 as we talk about reforms that we need for end of

1 life.

2 They spend much, much more money and for
3 no good reason. This -- the care is not going to
4 cure or help the person.

5 And it's certainly not because of the
6 patient's preferences. Surveys consistently show
7 that patients don't want intensive hospital-based
8 care when they die. They don't want to be on
9 breathing machines and tubes everywhere. They want
10 to die at peace and the home.

11 And Dartmouth found that this excessive
12 end-of-life care really harms patients. It costs
13 us billions of dollars a year in our health care
14 costs and it's misaligned with what patients want.

15 Even within a geographic area there's
16 large variations in the amount and cost of
17 end-of-life care amongst hospitals. Dartmouth
18 Atlas found that Medicare costs per enrollee for
19 the last two years of life, between 2000 and 2005,
20 averaged \$117,086 at Hahnemann Hospital and 71,633
21 at Fox Chase Cancer Center.

22 That's a difference of 50 [sic] percent.
23 Double the cost at Hahnemann, half the cost at Fox
24 Chase. And -- and both had the same outcome.
25 People died within two years of end of life.

1 But other academic studies have found
2 that Pennsylvania hospitals end-of-life care
3 intensity varies depending on how the hospital
4 staff routinely use specific life sustaining
5 treatments.

6 Now, certainly some patients come to
7 hospitals with an unexpected intensive care need
8 where it's appropriate to put them on these life
9 supports, but to have a patient with metastasized
10 cancer, who has an advance directive that says they
11 don't want that, and to go into a hospital and be
12 put on all those machines is not appropriate.

13 One Pennsylvania study found that
14 hospitals have a real fingerprint on how they use
15 intensive life supports.

16 And I talked to the researcher and she
17 said, I can tell you hospitals that routinely put
18 you on those things no matter what you want and the
19 ones that, perhaps like the ones your uncle went
20 to, where they had that conversation and they don't
21 do that.

22 So what this means for us in
23 Pennsylvania, and across the country, is that the
24 circumstances of our deaths, whether we die with
25 tubes and respirators rather than at home and the

1 cost of how much end-of-life care is for us may
2 depend more on where we live or which hospital we
3 end up than on what our advance directives says.

4 And this is very concerning and it's
5 something that needs a lot of attention.

6 Dartmouth Atlas research also found that
7 critical -- the critical role of discretionary
8 decision making by physicians, such as whether to
9 admit a patient to the hospital, refer to a
10 specialist, order diagnostic tests, or see the
11 patient more frequently can lead to wide variations
12 in end-of-life costs.

13 And this is often influenced by
14 supply-enticed demand. You got a lot of
15 specialists? You got empty hospital beds? You get
16 referred to the hospital instead of to hospice.

17 This was illustrated recently in our work
18 with primary care practitioners and their
19 chronic-care-patient-center-medical homework where
20 we have seven learning collaboratives going on
21 across the Commonwealth with 800 primary care
22 practitioners.

23 If they become NCQA certified, as the
24 patients enter medical home, submit their data
25 monthly and really working on make sure that all

1 their patients have evidence-based care, they get
2 enhanced payments from all the payers except
3 Medicare Fee-For-Service.

4 And we're really seeing a reduction to
5 hospital usage. We're seeing a reduction in
6 referral to specialists.

7 One of the payers that was involved was
8 talking to a specialist about this, and the
9 specialist said, I don't care whether or not this
10 reduces the number of patients that come from these
11 practices to me. What I'll do is just up how often
12 I see the other patients to maintain my -- my
13 standard of living.

14 So we really have to look at
15 supply-induced demand. We have to look at whether,
16 in fact, hospitals are using intensive life
17 sustaining support inappropriately. And we have to
18 look at some of the follow-the-money issues that
19 are involved in this issue.

20 Federal reforms will attempt to begin to
21 address some of these issues through bundled
22 payments and accountable care organizations, but
23 it's something that we in Pennsylvania have to pay
24 attention to and I wanted to make sure that it
25 was -- that you were aware of this as you address

1 this important issue.

2 Thank you.

3 CHAIRMAN MUNDY: Okay. Questions?

4 Ms. Torregrossa, we're not going into
5 certificate of need here.

6 DIRECTOR TORREGROSSA: I thought you
7 might think of that.

8 CHAIRMAN MUNDY: We're not -- no. No,
9 we're not going to -- you know, that's -- you know,
10 that's before the Insurance Committee, and I'm
11 hoping there will be a vote on that soon.

12 But it does raise the issue of supply and
13 demand, supply driving demand as opposed to
14 vice-versa, as it should.

15 What -- is there a legislative fix or is
16 this something that we're just going to continue to
17 discuss and make people aware of?

18 DIRECTOR TORREGROSSA: Well, certainly
19 New York has -- has taken one approach. And -- on
20 the supply side.

21 I think it's also payment reform. Right
22 now it's -- it's profitable for hospitals to
23 provide maximum end-of-life care for certain
24 payers. And so, you know, they're trying -- they
25 are rationalizing and -- I'm trying to do

1 everything possible for the patient, but it also
2 happens to help the bottom line.

3 So I think we have to -- to look at
4 payment reform as a way to more efficiency --
5 efficiently use our resources and align it with
6 what patients' preferences are.

7 And I don't think we have our payment
8 aligned in that manner right now.

9 CHAIRMAN MUNDY: Well, I -- I honestly
10 don't know -- I can't think of an initiative that
11 we could initiate as legislators.

12 So if you have ideas for legislation that
13 might be necessary, we would really like to talk to
14 you about that.

15 In fact, what I would like to do is
16 convene a task force of members of this committee
17 just to meet informally about -- after this hearing
18 to discuss, is there legislation that's needed in
19 these areas? Are there public policy concerns that
20 we can bring to the attention of the various
21 departments?

22 So any member of the committee who is
23 interested in -- in getting together to discuss
24 this should let me know.

25 Questions?

1 Representative Vulakovich.

2 REPRESENTATIVE VULAKOVICH: Thank you,
3 Madam Chairman.

4 I'll start backwards. You mentioned
5 about discretionary treatment in your statement.
6 Could you say that again what you -- what you said
7 there? I -- I -- I missed that.

8 DIRECTOR TORREGROSSA: Certainly.
9 There's -- what the Dart -- the Dartmouth Atlas
10 found was that a lot of the end-of-life costs that
11 were above normal in some of these hospitals and
12 for some of these specialists was for discretionary
13 treatment.

14 That is, how often you saw a specialist.
15 Did you see a specialist every week, every month,
16 every quarter? How often you were referred to the
17 hospital? Were you referred to the hospital for
18 tests or when you really were in need?

19 Diagnostic testing, how often did you go
20 for an x-ray, for a CAT scan, or that -- that --
21 there was a lot of discretionary referrals that
22 weren't necessarily medically necessary. In fact,
23 were not medically necessary.

24 REPRESENTATIVE VULAKOVICH: Okay. You
25 know, I don't know how you legislate something like

1 that when we -- we tend to get back to the idea
2 that with a lot of the primary physicians that
3 should, you know, be in control of your health and
4 guide you in other areas -- we talk so much about
5 that preventive health and everything else.

6 I don't know how you legislate something
7 like that and tell a doctor that, even though in
8 your opinion or in your conscience, you're saying I
9 believe this person should go see this specialist
10 and have this treatment done and -- somehow we're
11 going to legislate that because were putting
12 dollars on that.

13 I don't -- I don't know how you legislate
14 that.

15 DIRECTOR TORREGROSSA: I agree. I don't
16 think you do.

17 REPRESENTATIVE VULAKOVICH: And -- and I
18 think sometimes you just can't legislate things.

19 DIRECTOR TORREGROSSA: But I think you
20 can --

21 REPRESENTATIVE VULAKOVICH: You know?

22 DIRECTOR TORREGROSSA: You can have
23 payments that make hospitals, specialists, and
24 primary care providers be more efficient in how
25 they're utilizing health care and -- and that's

1 what we got to figure out.

2 Because right now the incentive is
3 exactly the opposite. You know, the more you do
4 the more you get paid. And -- and whether it's
5 necessary or not.

6 And so, of course, people are going to --
7 going to do that. And -- and -- and it's really --
8 and payment reform is something that we really need
9 to look at.

10 REPRESENTATIVE VULAKOVICH: What I would
11 be fearful of is that we would -- we would go
12 towards the way Medicare goes where they're not
13 paying the doctors near what it cost them to treat
14 patients and -- and, you know, we can't even afford
15 Medicare.

16 But I just think that, you know, we get
17 into a thing here where we talk about the doctors,
18 you know, relying on them, instead of people like
19 us telling doctors, giving them guidelines and
20 mandates and regulations on what they're going to
21 do, and -- and I understand. There's -- there's
22 good and bad in everything and there's always the
23 -- the dollar figure in there.

24 But, you know, most of these doctors
25 really have -- I mean when they took that oath,

1 it's something they always wanted to do their whole
2 life. And they worked long hours and they have a
3 lot of decisions and they go through a lot of
4 heartaches with their -- with their patients when
5 they -- when they establish their relationships
6 with them with going to the doctor's office.

7 And I don't know how you tell doctors,
8 you know, when they treat or don't treat. But I --
9 I think there's certain things that you go down a
10 really slippery slope when you try to legislate
11 those things. So --

12 DIRECTOR TORREGROSSA: I agree. Could I
13 give you an example of what we're doing on chronic
14 care?

15 We have -- we started in southeast
16 Pennsylvania. We have all the major payers,
17 including Medicaid HMOs. We know that in 2007 the
18 PHC board told us that hospitals charged \$4 billion
19 for avoidable hospitalizations; that is, if people
20 got the care that they needed in the community from
21 their primary care practitioner, they wouldn't have
22 needed that hospitalization and they wouldn't have
23 gotten so sick that they had to have that
24 hospitalization.

25 So we're wasting a lot of money there.

1 We're not paying our primary care doctors enough to
2 see patients with chronic conditions.

3 They got to see so many patients every
4 hour just to pay -- keep the lights on. So we're
5 in this conundrum where all the money is over
6 here. We're not paying enough here to get the
7 right outcome.

8 So what the -- what all the payers said
9 was, okay, if you transform how you provide primary
10 care, you make sure that all of your patients have
11 evidenced -- all the evidence-based care they need
12 for their chronic condition, we're going to take --
13 we're going to believe that we'll save some of that
14 money for -- from avoidable operations and if you
15 get certified as an NCQA, patients enter medical
16 home, if you -- if you get a level of a three,
17 we'll give you an extra hundred thousand dollars a
18 year.

19 And so what we found, one Medicaid HMO
20 found that -- that in the first ten months of doing
21 this their -- their hospitalization for diabetics
22 was reduced 26 percent.

23 So it was a combination of working with
24 the doctors to provide the appropriate care,
25 creating the financial incentives to spend the time

1 with the patient at the primary level rather than
2 just shooting them off to the specialist, avoiding
3 hospitalizations, and really appropriately
4 reimbursing physicians in payment reform.

5 And -- and we're hoping this kind of
6 thing is -- is going to work across Pennsylvania.

7 REPRESENTATIVE VULAKOVICH: I see your
8 point, and I'm not trying to be confrontational. I
9 just -- you know, I think sometimes we just mandate
10 so much and we over-regulate so much that we create
11 these problems and then we come back and try to
12 say, okay, now we got to do these mandates and
13 these regulations to control something that maybe
14 should have happened.

15 And I go to -- still come back to letting
16 the primary doctor do doctoring. Letting him make
17 his decisions and don't over-regulate.

18 And, you know, I -- I believe strongly in
19 my heart that these physicians -- they say there's
20 good and bad in everything, but they really have
21 the best interests of the -- of the patient in
22 hand.

23 I mean they took that oath, and -- and
24 most of these people, this is what they wanted to
25 be most of their lives, a doctor.

1 DIRECTOR TORREGROSSA: I agree with you.

2 REPRESENTATIVE VULAKOVICH: And I -- and
3 I -- this is a discussion for another day, but I
4 think letting doctors do what they want to do and
5 getting into some tort reform, I think we wouldn't
6 have to worry about all these intricate ways of
7 trying to settle these problems.

8 But I thank you.

9 Could I -- or, Madam Chairman, could we
10 have her testimony with her statistics and the
11 study that she has?

12 DIRECTOR TORREGROSSA: Yes, I'll provide
13 that to you. I'll attach the studies.

14 But I really suggest, if you have a
15 couple minutes, to Google Dartmouth Atlas and you
16 can -- they have the ability to -- for your area,
17 click on hospitals and click on these issues and
18 you'll be amazed at the variation in end-of-life
19 care, specialist referral, use of hospice or
20 nursing home. It's very fascinating.

21 And it's -- it's -- they've been doing it
22 for over 20 years.

23 REPRESENTATIVE VULAKOVICH: Thank you.
24 Thank you.

25 Secretary Hall, I wanted to -- I wanted

1 to make a comment on -- you said that you think the
2 policy that we should initiate is to try to
3 institutionalize end-of-life issues and medical
4 treatment.

5 How -- how do we go about generalizing
6 all people? Your mother obviously was a very
7 strong-willed person and had some attitudes. You
8 might say very positive attitudes about life and
9 death.

10 Some people joke about life and death.
11 I've seen -- gone to funerals where, you know,
12 they're there and they're in the midst of all the
13 people and they're carrying on regular
14 conversations while the deceased is over there, and
15 then the next month you're going to someone who
16 passed away of theirs and it's a totally different
17 situation.

18 So death, when it hits you personally,
19 puts a little different name on it.

20 But, you know, I absolutely know many
21 people that if they came in and they had cancer and
22 it looked pretty bad and you said, now, look, we're
23 going to try some treatment here but in case it
24 doesn't work, you know, we want to start talking
25 about -- maybe we need to talk to you about

1 hospice, I -- I think that you would take hope away
2 from them and even maybe destroy them or you would
3 literally put them into some type -- not that
4 they're not already in maybe some type of
5 depression.

6 But I just don't think you can generalize
7 this.

8 And sometimes I -- you know, I've thought
9 about it. I've gone through this with hospice with
10 my uncle where I had to take charge because of my
11 aunt and -- and everything and so I know a little
12 bit about it. But it was awhile ago. Things have
13 changed.

14 But the feelings are still there. And --
15 and -- and I just know some people, if you carry on
16 that conversation too early with them, you're going
17 to make them a mess.

18 So -- so do we -- how would you define
19 institutionalizing the end-of-life issues and
20 medical treatment? I -- I don't know. I'd like to
21 see you put that on paper, because if we would even
22 think of some type of legislation like that and --
23 and Dr. Straton, I believe he used the words about
24 people language. I always use the term eighth
25 grade language.

1 Because the last thing we need, like you
2 referred to, is medical people putting this in
3 words or the attorneys and their legalese.

4 How would you -- how would you put this
5 down on paper to institutionalize end-of-life
6 issues and medical treatment?

7 SECRETARY HALL: Well, let me say first
8 off that I don't think this is about taking
9 something away from people, taking hope away and
10 taking options away from people.

11 I think it's about giving people the
12 information so that they can make choices. And the
13 choices they make are not going to be uniform.
14 Somebody is going to choose hospice care or
15 palliative care based on their own sensibilities
16 and somebody with exactly the same diagnosis is
17 going to choose that they want to undergo
18 aggressive treatment to try to beat it. I think
19 that's a right that people have.

20 But they're also -- they also have a
21 right to know what the choices are, to be
22 presented -- and to have those choices presented on
23 equal terms.

24 You know, a key part of this discussion
25 that has entered our consciousness in the last 20

1 years is the conversation that you have with
2 doctors about routine surgical procedures right up
3 to the end-of-life care should revolve around the
4 concept of informed consent.

5 That patients have a right to consent and
6 that consent needs to be informed, which means that
7 they need to be provided with all the information
8 on the alternatives and on the risks and benefits,
9 the pros and cons, the chances of something working
10 versus the chance -- something -- something not
11 working so that they make a decision about which
12 course they want to pursue.

13 I think that that's -- I think that we do
14 a better job today than we did before. But in a
15 world where less than 40 percent of medical
16 students get training, less than 40 percent of
17 medical schools even offer an elective course in
18 palliative care. Fewer still have it as a
19 mandatory course requirement for graduation.

20 It's -- it's -- we're not at a place
21 where the kind -- the quality of information that's
22 provided to people so they can make a choice on
23 their own is really where it needs to be. And
24 that --

25 CHAIRMAN MUNDY: Can I interrupt for one

1 second? Just -- I want to follow up on --

2 REPRESENTATIVE VULAKOVICH: Sure.

3 CHAIRMAN MUNDY: And if I understood
4 Dr. Straton correctly, palliative care could be a
5 choice that's given along with aggressive
6 treatment.

7 SECRETARY HALL: Absolutely.

8 CHAIRMAN MUNDY: So when -- and the other
9 thing is I heard you say, at least I thought I did,
10 that we need to make sure that the conversation
11 happens, that we need to make -- institutionalize
12 the conversation.

13 SECRETARY HALL: That -- that -- if -- if
14 it -- if the --

15 CHAIRMAN MUNDY: The information.

16 SECRETARY HALL: If the words came out of
17 my mouth differently than that, I apologize. What
18 I --

19 CHAIRMAN MUNDY: That's what I heard you
20 say.

21 SECRETARY HALL: What I think should
22 happen --

23 CHAIRMAN MUNDY: That we need to
24 institutionalize the conversation. Not
25 institutionalize what people's -- what people must

1 choose or what doctors must say. But simply tell
2 people this is what your diagnosis is, this is what
3 I would recommend that the course of treatment be,
4 and here are your options.

5 SECRETARY HALL: Here are the range of
6 options. And here -- here's the -- here's the
7 efficacy of one versus another.

8 So that you have -- I think that that
9 should be -- particularly for people who are facing
10 the potential for life-ending disease, I think that
11 we have a responsibility to give them that
12 information.

13 CHAIRMAN MUNDY: Go ahead.

14 REPRESENTATIVE VULAKOVICH: And I don't
15 disagree with that at all. I understood it
16 completely that you were talking about the
17 conversation.

18 But in that conversation you're talking
19 about talking about not only palliative care,
20 because that I understand. Because you want to
21 address the symptoms that go along with it, which I
22 got to tell you, I thought most doctors who handled
23 this stuff would know that something has to follow
24 up with the -- the symptoms, you know, that you
25 have, like the nausea afterwards. You would just

1 think that would happen.

2 So that's something that needs to be
3 addressed. But when you're talking about the
4 actual end of life and just talking about when you
5 throw hospice in there, my point being is how do we
6 judge at what time you're going to have that
7 particular part of that conversation?

8 Because all people are different and --
9 and I don't think anybody can sit here and say
10 that -- I agree with you, choice, options, get all
11 that information. But for certain people that
12 plays into a certain time in their life.

13 Now, their doctor may know them so
14 personally that they know exactly when to do that.
15 If they don't, you know, the only other people that
16 can help them to, say hey, I know how my mom is and
17 I know how my dad is.

18 For example, you want to have that
19 conversation with me, I'm like your mom. You can
20 have that with me. I don't know if you could do
21 that with my wife. But I know that.

22 And I don't want some legislator or
23 someone else that has some philosophy making that
24 on their own. I want to be part -- I want to be
25 part of that conversation for my spouse if it needs

1 to be.

2 So all I'm saying here is that I agree
3 with so much of all of what you said, but there's a
4 slippery slope, I think, that goes along with this
5 that we can't generalize people. And I do not want
6 to get into things with mandating things to doctors
7 and -- and -- and putting certain regulations in
8 that I don't know that you can do.

9 Now, I could be totally wrong. I -- I
10 couldn't come close to your expertise in this. But
11 it's me thinking out of the box, just this is how I
12 am, and -- but I'll tell you, I'm really glad I
13 attended this hearing today because this -- this is
14 one of the better hearings I've been to.

15 And I agree so much with what you said,
16 with all three of you, what you say. But I just
17 have some reservations there. And -- and I don't
18 know. Maybe I'm not putting them in the right
19 words, but I want to thank all of you.

20 And, Dr. Straton, what I like about you,
21 there's no spin with you. You really speak
22 totally -- no talking points. It's from the heart,
23 and I appreciate that. Thank you.

24 Thank you, Madam Chairman.

25 CHAIRMAN MUNDY: Representative Swanger.

1 REPRESENTATIVE SWANGER: Thank you, Madam
2 Chair.

3 And thank you, Secretary Hall and
4 Director Torre -- Torregrossa? Is that right?

5 Thank you for being here. And this
6 certainly has been a very valuable experience.

7 And also the doctor, I thank him, too.

8 But I'd like to talk about the movement
9 in our country as we get closer and closer to
10 single payer health care. Much of the resist --
11 resistance, I think, is coming from seniors who
12 fear that once they reach a certain age they will
13 be denied life-saving treatment and coverage and
14 that age would be determined by the government.
15 And, therefore, they'll be facing this end-of-life
16 situation much sooner than they would like.

17 I see most -- a lot of us in this room
18 are senior citizens, and I'm just wondering is this
19 what we have to look forward to in our future as
20 government resources and other resources for health
21 care become more and more scarce.

22 Some people have said, well, this will
23 never happen in our country. But, in fact, it's
24 happening in Great Britain. It's happening in
25 Canada.

1 And I believe from information I've
2 received and shared with the Chairman that it is
3 happening in our country in the state of Oregon
4 where seniors have been denied care because of
5 their age and instead offered lethal drugs in order
6 to end it all if the pain becomes too unbearable.

7 Can you comment on this? Is this what we
8 have to look forward to?

9 SECRETARY HALL: Do you want to go first?

10 DIRECTOR TORREGROSSA: I certainly hope
11 not.

12 SECRETARY HALL: Yeah. I -- let me just
13 say that I -- I don't think that there's a -- any
14 public appetite for that future in -- in the United
15 States.

16 But I do think that the surveys that have
17 been done over and over again indicate that the
18 public feels strongly about having the ability to
19 control their own destiny and decide their own
20 course of care.

21 And overwhelmingly they say -- and this
22 gets back to the issue of conversations we have
23 with our -- our friends and family members and
24 acquaintances -- that they say, I wouldn't want to
25 have extraordinary measures. I wouldn't want to be

1 kept alive artificially. I want to die with
2 dignity and die peacefully.

3 But they want to make sure that they have
4 a chance to exercise that right as well and they
5 have the information to do that.

6 So I think our focus as we go forward in
7 health care reform at both the state and national
8 level ought to be on making sure that we assure
9 people that they'll have a right to put in their
10 own vote on that.

11 DIRECTOR TORREGROSSA: One thing that
12 some programs are doing is something called shared
13 decision making.

14 Michael's mother didn't get good
15 information. She was led along to think that if
16 she went through all these things she would be
17 there with her seven children. She didn't get
18 information that would have perhaps made her do
19 differently at some point or not.

20 Oncologists will be -- I mean their job
21 is to make you have hope and tell you, okay, we're
22 going to fight this together and da da da da da.
23 Surgeons, their job is to tell you, okay, we're
24 going to cut it out. Yeah, I think I got it all.
25 Da da da da da.

1 One thing that Dartmouth is doing is
2 realizing that the -- that these health care
3 providers have to have that happy face and
4 whatever, and they're doing something called shared
5 decision making. Only if the patient wants it.
6 Which is going to a neutral provider and getting
7 kind of what are the odds here, what are the
8 choices.

9 Now, maybe your wife wouldn't want to do
10 that and maybe you would want to do that. Before
11 you made the decision, am I going to have this --
12 this big operation or am I going to go through
13 chemotherapy?

14 And they've found that people feel much,
15 much better -- I mean because they'll go into the
16 shared decision making and one might do one thing
17 and one might do another, but they feel much more
18 comfortable about that decision and they're -- and
19 they're much more at peace with the outcome.

20 And that -- that's maybe something we
21 should look at.

22 REPRESENTATIVE SWANGER: Yes. And I hope
23 we continue to have those choices and not have the
24 government make those decisions for us.

25 Thank you.

1 DIRECTOR TORREGROSSA: I agree.

2 CHAIRMAN MUNDY: Representative Kortz.

3 REPRESENTATIVE KORTZ: Thank you, Madam
4 Chairwoman.

5 And thank you both for your testimony
6 today.

7 Secretary Hall, it was mentioned a little
8 while ago that fewer than 40 percent of the medical
9 schools offer elective courses in palliative care
10 and even fewer than that have mandatory courses.

11 What would you recommend that we as a
12 committee do to address that?

13 SECRETARY HALL: Well, I'm hesitant to
14 jump right to legislation to address that. But I
15 think that there's -- we have some of the best
16 medical schools in the country in this state and we
17 turn out some of the best-trained physicians.

18 And I think there's a conversation that
19 could happen and should happen about the curriculum
20 and the training that people have as they are
21 coming out of schools so that we make sure that
22 physicians are equipped with the skills to -- to
23 meet the needs of patients who want to have this
24 kind of information.

25 If it -- I think it's the kind of thing

1 that the -- some schools have understood the wisdom
2 of doing and have pursued that. And I -- I think
3 the place to start would be to shine a light on it
4 and then figure out where you go from there.

5 REPRESENTATIVE KORTZ: Maybe some
6 follow-up public hearings?

7 SECRETARY HALL: Well, I think there
8 are -- I think there are folks from those schools
9 that should be part of the conversation about the
10 right way to go.

11 And I think including in that would be
12 people like Dr. Straton and his colleagues around
13 the state who have a keener sense than I of what
14 would be useful in terms of the training that
15 physicians get.

16 REPRESENTATIVE KORTZ: Thank you.

17 CHAIRMAN MUNDY: Chairman Hennessey?

18 REPRESENTATIVE HENNESSEY: Thank you,
19 Madam Chairman.

20 Ann, you had suggested for -- you had
21 stated that some hospitals spend more money
22 routinely on end-of-life care than others and then
23 suggested that there are doctors who are routinely
24 ignoring advance directives and involving the
25 patient in -- in extended -- you know,

1 life-extending services.

2 Now, I guess what I'm trying to figure
3 out is, first of all, I'm assuming that one is
4 happening -- that those doctors are practicing in
5 those hospitals where their costs are routinely
6 high or higher for end-of-life services; and,
7 secondly, I guess the more important question would
8 be, how is it happening?

9 Do -- do the doctors -- you know, are
10 they aggressive in trying to talk the patients into
11 overruling their own decisions and changing their
12 minds? Do they get family members to do it? Do
13 they just ignore the advance directive?

14 What's -- what do you think is happening
15 that is allowing this to happen?

16 DIRECTOR TORREGROSSA: What I quoted were
17 studies. I'm not saying -- I mean I -- I don't
18 have the personal information myself. I'm quoting
19 studies.

20 I think what happens --

21 REPRESENTATIVE HENNESSEY: Okay.

22 DIRECTOR TORREGROSSA: Excuse me. Is
23 what happened with your mother. And some of the
24 issues on -- your -- your loved one's having
25 trouble breathing.

1 REPRESENTATIVE HENNESSEY: Lisa is
2 getting you water right now.

3 DIRECTOR TORREGROSSA: Thank you. Pardon
4 me.

5 You rush her to the hospital.

6 Thanks so much.

7 She has this directive. If you go to
8 Hospital A, they'll put her on a respirator and
9 say this -- this -- hopefully this will help her.
10 You, da da da da da.

11 You don't know. Is this it or, you know,
12 will this be it? So they have -- they are -- have
13 the tendency to much more aggressively use these
14 life-sustaining things without saying, time out.
15 Your mother has metastasized cancer. We can put
16 her on the respirator or we can make her
17 comfortable. Which would you like us to do?

18 So Hospital A is going to -- unless you
19 say, stop right now, don't do this, is going to put
20 her on the respirator and you don't know if this is
21 it. If it's -- it's such a hard and horrible
22 time. You're -- you're not thinking straight.
23 It's just terrible.

24 You've got nieces coming in, and they're
25 saying, oh, we've got to do something, and they

1 haven't been involved in the long-life care of this
2 whole problem.

3 And it happens. I'm not saying doctors
4 ignore -- pardon me -- advance directives. I
5 think -- I think some are much more purposeful when
6 there is a situation like that to say, all right,
7 time out, family. Do we really want to use this
8 respirator at this time? This may be the time to
9 make your mother comfortable.

10 Another hospital will put her on the
11 respirator, maybe ask about advance directives
12 later, but are much more aggressively using
13 life-sustaining services.

14 And as I told you, the researcher that I
15 talked to said that hospitals really have a
16 fingerprint. That you can look at the use of these
17 life-sustaining instru -- services and they vary
18 widely by hospital.

19 REPRESENTATIVE HENNESSEY: Okay. But it
20 sounds like you're saying that there's not a -- not
21 an ignoring of an advance directive, but maybe not
22 seeking out information on whether a person who
23 presents at a hospital and needs care has ever --
24 has ever executed an advance directive.

25 Is it assumed that they didn't and go

1 through -- you know, put her on the life-sustaining
2 care and initiate that process and worry about
3 whether or not an advance directive has been
4 executed at a later time?

5 DIRECTOR TORREGROSSA: And not letting
6 the person who has the power of attorney know what
7 the situation is, that this is probably your
8 mom's -- sorry -- you know, your mom is fading
9 fast.

10 REPRESENTATIVE HENNESSEY: Okay.

11 DIRECTOR TORREGROSSA: We can put her on
12 a respirator and see if she does any better or we
13 can make her comfortable. What -- what would you
14 like us to do?

15 SECRETARY HALL: Chairman Hennessey, can
16 I make a point?

17 REPRESENTATIVE HENNESSEY: Thank you,
18 Ann.

19 SECRETARY HALL: You know, a few years
20 ago, and I lost track of exactly how long it was,
21 but not too long ago, I believe the Harvard Medical
22 School published a study in the New England Journal
23 of Medicine where they studied over time the -- the
24 contents of durable powers of attorney for health
25 care and then looked at the course of treatment and

1 compared what was in the power of attorney for
2 health care, what the instructions from the patient
3 were, compared to what action the physician took,
4 compared to what action the surrogate, the -- the
5 agent took.

6 And what they found was that in a
7 distressingly high number of cases the action that
8 the physician took was not consistent with what was
9 in the power of attorney for health care.

10 But what I found more dismaying is that
11 the -- in more than half of the cases the action
12 that the agent, the surrogate, took was not
13 consistent with what was in the power of attorney
14 for health care.

15 When that report came out, there was a
16 fair amount of discussion about what should we do
17 about that? How can we assure that people are not
18 ignoring people's advance directives?

19 And I will just share my personal view
20 that I don't think that that's the thing that --
21 kind of thing that's susceptible to law.

22 I think we're going through a cultural
23 change. I think the medical profession itself has
24 been going through change for the last two
25 decades. And the respect for these kinds of things

1 is much higher than it was before -- 20 years ago
2 and it will be much higher 20 years from now as we
3 all become more accustomed to the role and
4 responsibilities that the physicians have and
5 the -- and the obligations and the role that
6 patients want to play in this.

7 We -- the kind of public discourse that
8 Dr. Straton talked about, conversations that happen
9 in communities and hospitals is an important piece
10 of it.

11 Making sure that there are routine
12 procedures in place for making -- for providing
13 this information to people is a piece of it.

14 I think that there's no question that
15 advance directives get disregarded on a regular
16 basis in all too many cases, but we -- we have some
17 of the methods for improving on that in our hands
18 now.

19 Many hospitals today have ethics panels
20 that cases can be referred to if there's a dispute
21 either between family members or a dispute between
22 a physician and the -- and the surrogate.

23 And if -- if an individual who is
24 designated as the agent feels strongly that the
25 mother, or whoever it is that did the power of

1 attorney, would have wanted something and finds
2 themselves in conflict with -- with a physician,
3 they typically have the authority under that power
4 to change physicians or go to a different hospital
5 or do something else.

6 That's -- and that was one of the
7 purposes of creating those advance directives in
8 the first place.

9 This is the kind of thing that I think
10 society is still learning how to do.

11 REPRESENTATIVE HENNESSEY: Thank you very
12 much.

13 CHAIRMAN MUNDY: I --

14 DIRECTOR TORREGROSSA: Could I just add
15 one thing on --

16 CHAIRMAN MUNDY: I --

17 DIRECTOR TORREGROSSA: -- on that? I
18 think when you're given the responsibility of -- of
19 terminating treatment for a loved one, it's -- it's
20 a horribly brutal position to be put in, particular
21 if it's someone you love.

22 And so often when you're given that
23 authority, they might tell you the extreme case,
24 you know, I'm brain dead or whatever, but the
25 in-between stuff you don't have that discussion.

1 There's a wonderful tool out there -- and
2 I'll include the link for it in my testimony --
3 that really takes you through seven scenarios
4 and -- and you can fill it out and give it to the
5 person who has the power of attorney.

6 It goes from the extreme of I'm brain
7 dead. I'm on machines. There's no hope. You
8 know, what would I want? Advanced -- you know,
9 aggressive treatment, palliative care, nothing.

10 To -- to the other extreme of you're
11 involved in an automobile accident. You're being
12 rushed to the hospital. There's a good chance of
13 your recovery. You probably want aggressive
14 treatment, you know, in that case.

15 And then they have five other kind of
16 variations -- I mean less extreme things going
17 down.

18 And so that it really, I think, helps
19 someone who has a power of attorney to really know
20 what the person would want and give -- perhaps give
21 you the strength to overcome the emotional load
22 that -- that denying treatment requires.

23 SECRETARY HALL: And I'd like to just add
24 to that that one of the things that you learn the
25 hard way in this process is filling out one of

1 these forms.

2 It's hard enough when there's not even a
3 -- an advance directive, but to think that filling
4 out a durable power of attorney for health care or
5 signing a living will is going to take care of this
6 isn't -- isn't the case.

7 It really gets back to the conversation
8 that Dr. Straton was having with the committee. It
9 has to do with knowing the mind of the person -- of
10 the family member. Being able to stand in their
11 shoes and say, even with the benefit of advance
12 directive, this is what they would have wanted.

13 A classic case that we use in ethical
14 trainings that we did with physicians had to do
15 with something very similar to -- to what Ann was
16 talking about.

17 A 34-year-old individual, otherwise in
18 good health, has signed an advance directive saying
19 he wants no extraordinary measures, and then an
20 ambulance responds to his home finding that he's
21 aspirated a grape.

22 So the question is do you withhold the
23 treatment that in -- in conformance with the
24 advance directive, that says no extraordinary
25 measures, or do you figure out you clear the air

1 pathway so that he can continue breathing again?

2 It's -- that's -- that's a situation that
3 we see all the time where you have to go beyond
4 what's written on the piece of paper and try and
5 understand what the person would have wanted.

6 And it's an example of how this is an
7 area that's not black and white. That you -- too
8 often it is gray, and the only way you find your
9 way through that grayness is by having a quality --
10 and this is where I wind up and it goes back to
11 what I've said many times today -- a quality of
12 conversation between the individual and the family
13 members, between the individual and the doctors,
14 that gives you insight into their minds and
15 preferences and wishes and sensibilities so that
16 you can find your way through those decisions.

17 REPRESENTATIVE HENNESSEY: Thank you very
18 much.

19 Thank you, Madam Chairman.

20 CHAIRMAN MUNDY: As I look through this
21 report, which I thought was really interesting,
22 this end-of-life -- Improving End-of-Life
23 Experiences for Pennsylvanians, the one that struck
24 me about the Departments of Aging and Public
25 Welfare is that the Departments of Aging and Public

1 Welfare should reverse the decision that restricts
2 people on the Medicare hospice benefit from also
3 receiving home-based services through the PDA
4 waiver program and reinstate community choice for
5 people in need of waiver services and Medicare
6 hospice.

7 If it's simply a question of reversing a
8 decision, why can't we just do that?

9 SECRETARY HALL: In my earlier testimony
10 I indicated that we have a draft policy directive
11 circulating right now that intends to harmonize
12 those two programs instead of having them be in
13 conflict with each other.

14 CHAIRMAN MUNDY: Well, was the -- was the
15 old policy the right policy? Why -- I mean I'm not
16 sure why we have to go through a lengthy process.

17 SECRETARY HALL: Well --

18 CHAIRMAN MUNDY: Why not just put it back
19 the way it was?

20 SECRETARY HALL: Well, historically --
21 historically the CMS had communicated to the states
22 that the -- that hospice services and long-term
23 care waiver services could not be received
24 simultaneously.

25 CHAIRMAN MUNDY: Okay.

1 SECRETARY HALL: This was interpreted by
2 the states as saying if you're -- if you're on
3 hospice you couldn't get the waiver and vice-versa
4 and you had to choose one or the other.

5 In December of 2008, CMS issued a policy
6 clarification that signaled new flexibility on
7 their part on this issue, and we've been in
8 conversation, both with our hospice community, with
9 Vicki Hoak and her folks at Homecare Association
10 and the Area Agencies on Aging, to craft a new
11 policy which takes advantage of that more flexible
12 thinking at CMS.

13 CHAIRMAN MUNDY: So it's more CMS
14 mischief?

15 SECRETARY HALL: Well, I mean I think --
16 I think that historically -- and this goes back to
17 work that I've done in earlier parts of my
18 career -- a great frustration here has been CMS's
19 inflexibility on this.

20 That having been said, I think that
21 states for too long just took that lying down and
22 didn't say, well, why is that? That makes no
23 sense.

24 And I think that's what's starting to
25 turn around.

1 CHAIRMAN MUNDY: Okay. And then before
2 you leave, I just want to highlight two other
3 recommendations -- and for committee members who
4 haven't had the chance to review the end-of-life
5 report, there is a set of recommendations in the
6 back and, what, there are some -- how many -- 160
7 recommendations, but I can really -- as I looked
8 through them, I could only find really two that
9 required legislation.

10 One was the legislature should update
11 advance directive law to assist in empowering
12 surrogates, assigning default surrogates,
13 broadening the legal definitions surrounding
14 terminal illness, standardizing and simplifying
15 advance directive procedures and forms, and
16 mandating the development of a statewide HIPAA
17 compliant registry for advance directives.

18 Are you aware whether there's any such
19 legislation before the Judiciary Committee or any
20 other committee to do that?

21 DIRECTOR TORREGROSSA: That was done with
22 Act 169.

23 SECRETARY HALL: Yeah.

24 CHAIRMAN MUNDY: Does that need
25 updating? That was 2006.

1 DIRECTOR TORREGROSSA: The -- the
2 potentially outstanding work is on the POLST,
3 physician's order for life-sustaining treatment.

4 CHAIRMAN MUNDY: I'm sorry. I couldn't
5 hear what you said.

6 DIRECTOR TORREGROSSA: I'm sorry. It's a
7 disease.

8 CHAIRMAN MUNDY: Sorry about that.

9 DIRECTOR TORREGROSSA: I think there may
10 be some -- some work that needs to be done on the
11 POLST, the physician's order for life-sustaining
12 treatment. And I think the Department of Health is
13 in the process of doing that.

14 CHAIRMAN MUNDY: That was Recommendation
15 Number 2.

16 DIRECTOR TORREGROSSA: The legislation, I
17 think, created a process to do that. And that, I
18 think, is the only thing that needs updating on
19 that, sure.

20 CHAIRMAN MUNDY: Okay. So even though
21 this -- this -- this report and the
22 recommendations -- oh, they're from 2000 -- okay.
23 Sorry.

24 SECRETARY HALL: I think in direct
25 response to that report, Act 169 was passed. It

1 set up the Life-Sustaining Wishes Advisory
2 Committee, and that committee was charged with
3 developing some of the things that the report
4 called for, including updating the physician order
5 process.

6 CHAIRMAN MUNDY: Okay. And then the only
7 other one that I see -- and correct me if you see
8 others -- is Number 6, the Pennsylvania legislature
9 should increase funding for scholarships, offer
10 incentives for advanced training or certification
11 in palliative care, such as the end-of-life nursing
12 education consortium and the education on
13 palliative and end-of-life care programs or board
14 certification.

15 Do you know where we are on that? Is
16 there anything --

17 DIRECTOR TORREGROSSA: I don't --

18 CHAIRMAN MUNDY: -- pending on that?

19 DIRECTOR TORREGROSSA: -- believe that
20 has happened.

21 CHAIRMAN MUNDY: Well, obviously funding
22 for anything at -- at the moment is problematic.

23 DIRECTOR TORREGROSSA: Is very difficult.

24 CHAIRMAN MUNDY: But these other
25 certifications, anything pending with the medical

1 education institutions?

2 DIRECTOR TORREGROSSA: Not that I'm aware
3 of.

4 CHAIRMAN MUNDY: Okay. All right. Thank
5 you very much. Appreciate your being here.

6 DIRECTOR TORREGROSSA: Yep.

7 CHAIRMAN MUNDY: Thanks for your
8 testimony.

9 SECRETARY HALL: Thank you.

10 DIRECTOR TORREGROSSA: Thank you.

11 CHAIRMAN MUNDY: Oh, sorry, Deb.

12 REPRESENTATIVE KULA: That's okay.

13 Just -- just as you made that statement and -- and
14 they talked about maybe incentives or whatever,
15 what we talked about earlier was medical schools
16 requiring this.

17 I mean that -- that seems that eventually
18 that would fill the gap if we can bring about more
19 training in the medical schools without really
20 having to do separate training for, say, other
21 individuals.

22 It seems that if we can get doctors to
23 graduate from medical school with this training it
24 may be able to fill that gap. Just a comment.

25 CHAIRMAN MUNDY: Thank you.

1 REPRESENTATIVE KULA: Thank you, Madam
2 Chair.

3 CHAIRMAN MUNDY: Thank you. I really
4 appreciate Susan Gerhart's patience with us. We're
5 going to ask her to come forward now. National
6 Director of Reimbursement and Outcomes with
7 AseraCare Hospice.

8 Thank you, Ms. Gerhart, for being here,
9 and thank you for sitting so patiently while the
10 committee asked so many questions.

11 You can begin whenever you're ready.

12 DIRECTOR GERHART: Thank you.

13 CHAIRMAN MUNDY: This is true. Go
14 ahead.

15 DIRECTOR GERHART: Good morning and thank
16 you Chairpersons Mundy and Hennessey and committee
17 members.

18 As you said, my name is Susan Gerhart and
19 I'm the National Director of Reimbursement and
20 Outcomes for AseraCare Hospice. I'm also a member
21 of the Advisory Council for the Lancaster County
22 Office of Aging.

23 I'm a past president of the Pennsylvania
24 Homecare Association, and I was a member of
25 Governor Rendell's task force that developed the

1 end-of-life report that you currently have in
2 front -- in front of you.

3 I commend the committee for holding this
4 hearing to stimulate further discussion concerning
5 end-of-life experiences for Pennsylvanians and to
6 explore the next steps that are necessary to
7 improve end-of-life care in Pennsylvania.

8 AseraCare Hospice has 12 hospice agencies
9 throughout Pennsylvania that provide services to --
10 for more than 800 families, patients and families
11 on any given day.

12 We take great pride in our
13 family-centered approach which ensures the needs
14 and wishes of both our patients and their family
15 members are met throughout the hospice experience.

16 Hubert H. Humphrey stated, it was once
17 said that the moral test of government is how that
18 government treats those who are in the dawn of
19 life, the children; those that are in the twilight
20 of life, the elderly; and those who are in the
21 shadows of life, the sick, the needy, and the
22 handicapped.

23 That statement still resonates well
24 today. The Improving End-of-Life Experience for
25 Pennsylvanians report notes that providing quality

1 end-of-life experiences for all Pennsylvanians is
2 to -- a challenge of increasing urgency and one
3 that must be tackled by all of us, legislators,
4 government officials, medical professionals,
5 educators, activists, and citizens.

6 But little progress has been made since
7 this report was released in 2006 as families
8 seeking and utilizing hospice and end-of-life
9 services in Pennsylvania still face daunting
10 challenges in accessing these services.

11 Hospice use remains low, and less than a
12 quarter of Pennsylvania residents die at home, even
13 though they say that is their -- they would prefer
14 to spend their remaining days at home.

15 What is hospice, palliative care,
16 end-of-life care?

17 I think Dr. Straton verbalized that very
18 well this morning, and I had never heard of hospice
19 put in that -- in that verbiage of insurance
20 defined but that was -- that was excellent. I
21 noted that, doctor. Thank you.

22 So hospice care and palliative care and
23 end-of-life care, they're all used simultaneously,
24 inter -- interchangeably, and I think it does
25 produce confusion among people. And so I would --

1 I would just urge you again to kind of review those
2 definitions. They really kind of all intermingle
3 and interact with one other.

4 Advances in modern technology and
5 breakthroughs in modern medicine have allowed
6 people to live longer resulting in an increase in
7 the number of people living with chronic
8 illnesses.

9 In addition, Pennsylvania today is faced
10 with a growing elderly population. This
11 population, people age 65 and older, comprise 15
12 percent of Pennsylvania's total population. Of
13 that group, the number of people age 85 and older
14 is projected to double to seven million by 2020.

15 These facts help us shape our discussion
16 here today. How can we collectively improve access
17 to hospice, palliative care, and end-of-life care
18 through a better coordination of services within
19 the financial confines of today's Medicare and
20 Medicaid budgets?

21 As a nation, Medicare currently spends 27
22 percent of its total dollars on people who are in
23 the last year of life. About 70 percent of the
24 people who die each year are covered by Medicare,
25 with about 13 percent also covered by Medicaid.

1 An independent study at Duke University
2 in 2007 showed that patients receiving hospice care
3 cost the Medicare program about \$2,300 less per
4 patient than those who did not receive hospice
5 care, accounting [sic] to annual savings of more
6 than \$2 billion.

7 These same kinds of savings could
8 potentially be achieved in the Medicaid program
9 through better coordination of hospice services
10 between various state Medicaid providers and
11 programs.

12 As the end-of-life report noted, care for
13 people who are in the last phases of life is often
14 delivered in a variety of health care settings,
15 including acute care hospitals, skilled nursing
16 facilities, inpatient hospice units, and, where
17 people want to spend their last days, if possible,
18 at home.

19 One way to better coordinate this care is
20 by allowing patients to assess Medicaid services
21 necessary to allow them to remain home.

22 We support the draft bulletin, from July
23 2nd, 2009, that was created by the Office of
24 Long-term Living. The bulletin clarifies the
25 participation of consumers in aging waiver who are

1 seeking hospice benefits.

2 Currently, the AAAs must contact the
3 Office of Long-term Living to clarify questions or
4 concerns regarding the addition of waiver
5 services. We strongly urge this bulletin's speedy
6 adoption.

7 Hospices, by definition, provide the core
8 services of nursing, medical social services,
9 counseling, and aide services to a hospice patient
10 and their family.

11 The hospice benefit that was designed to
12 support care givers of that hospice patient. It
13 was not designed to be an all-encompassing benefit
14 that provides continual care giver services.

15 This is an important distinction when it
16 comes to discussing the role of the aging waiver
17 [sic] has in conjunction with hospice care.

18 The role of hospice is to effectively
19 help the patient to manage symptoms related to
20 terminal illness, including support of care
21 givers. This support of care givers is offered by
22 volunteers and, when appropriate, through
23 short-term respite care. However, primary care
24 givers remain family and friends.

25 Yet many patients do not have access to

1 an adequate support network in their home. As a
2 result, many patients are left to spend their final
3 days in hospital or long-term care facility rather
4 than at home because they cannot access adequate
5 home and community-based services to allow them to
6 remain home.

7 Home and community-based services assist
8 patients in being able to remain at home by
9 providing them with assistance with activities of
10 daily living. Many people are denied access to
11 these services through the aging waiver because
12 they are receiving hospice services.

13 While we support the administration's
14 efforts to ensure that Medicare is the payer of
15 last resort, it is important to realize that home
16 and community-based services offered under the
17 aging waiver program are not being used in place of
18 hospices-covered care but rather is a compliment to
19 the hospice benefit.

20 That is why we strongly support the
21 report recommendation that the Departments of Aging
22 and Public Welfare should work to reverse policies
23 that restrict people on the Medicare hospice
24 benefit from also receiving aging waive -- waiver
25 services.

1 Under the new conditions of participation
2 for hospice that were just effective last year,
3 Medicare CMS allows for coordination of care
4 between these two programs.

5 In the -- in the Section 418.76 entitled
6 Hospice aide and homemaker services, it states:
7 Services under the Medicaid personal care benefit
8 may be used to the extent that the hospice [sic]
9 routinely service a hospice patient's family in
10 implementing a patient's plan of care.

11 The hospice must coordinate its hospice
12 aide and homemaker services with the Medicaid
13 personal care benefit to ensure the patient
14 receives the hospice aide and homemaker services he
15 or she needs.

16 The hospice benefit is not intended to
17 replace a primary care giver. Rather, it should
18 offer the expertise and support needed to live
19 better at the end of life. This would also allow
20 people to die at home rather than in a more costly
21 environment; that is, a hospital or a nursing
22 home.

23 While we recognize that there are a
24 myriad of quality recommendations that will assist
25 the state in advancing hospice care, the need to

1 support patients and their families in the home is
2 paramount.

3 People should have a choice where to
4 die. That choice is a personal one and it should
5 be based on what is comfortable, not if -- not
6 based on one in which a care [sic] is
7 reimbursable.

8 I'd just like to give you two of -- two
9 different examples of patients in which one that we
10 could coordinate services with waiver and what the
11 outcome was, and one that we were not able to
12 coordinate services.

13 In the first example we had an
14 86-year-old gentleman at home with his 84-year-old
15 wife and they did have the waiver services in
16 place. As his -- he was end-stage cardiac.

17 As his cardiac condition worsened, his
18 physician did suggest hospice care. We were
19 allowed to enter the care of that patient and
20 coordinate our services with the waiving -- the
21 waiver services.

22 The waiver services provided blocks of
23 time during each day as well as assistance with
24 additional activities of daily living, washing,
25 cooking, that sort of thing.

1 We, on the other hand, came in and
2 assisted that family with their medications,
3 supplied oxygen for the gentleman, supplied a
4 hospital bed so that he could sleep in an upright
5 position more comfortably rather than in the bed
6 that he was on trying to prop himself with 50
7 million pill -- pillows.

8 But it was a perfect example of how the
9 two programs worked beautifully together. They
10 went in the morning. We went in the afternoon.
11 They went back in the evening for a different block
12 of time.

13 Together, we gave that 84-year-old spouse
14 a lot of support and -- and care. We were also
15 able to provide them with psychosocial support,
16 emotional support, spiritual support.

17 In addition, once her husband passed
18 away, part of the hospice benefit is 13 months of
19 bereavement.

20 So we remained with her for the next 13
21 months providing her with the grief counseling and
22 support she needed to move her life forward without
23 her lifelong partner.

24 The other instance did not have such a
25 pleasant outcome. In this case it was a

1 70-year-old woman with metastatic cancer living
2 with her daughter and her son-in-law. In this
3 case, hospice was in caring for her. She was
4 independent during the day. Daughter and
5 son-in-law were there in the evening.

6 But as she began to decline, the hospice
7 services were not able to increase to meet her
8 needs throughout the day when her daughter, who was
9 a teacher, was at school. And we were not
10 successful in -- in bringing in the waiver
11 services.

12 Ultimately they paid a few months
13 out-of-pocket for some private care during the day
14 and she eventually ended up living her final days
15 in a skilled nursing facility, which is what
16 neither she nor her daughter had intended.

17 But it was an example of if we had co --
18 could have -- could have coordinated with waiver
19 services I'm sure she could have remained at home
20 with her daughter.

21 Another challenge facing hospice patients
22 is the portability of advance directives, living
23 wills and do-not-resuscitate orders. Better
24 education is needed for health care providers,
25 families, and consumers for these various methods

1 for people -- patients to express their wishes and
2 the standard recognition of each of these documents
3 throughout this health care system.

4 Despite having a DNR, a hospice patient
5 in a personal care home must have an ambulance
6 called for them as described in the Licensing
7 Measurement Instrument for the Personal Care Home
8 Regulations, 55 Pa. Code, Chapter 2600.

9 As it states, if there is a DNR order and
10 the resident requires emergency medical services,
11 the home must contact emergency medical personnel.
12 The home should inform the medical personnel of the
13 resident's DNR order.

14 However, even with the DNR order, the
15 home must still call emergency medical support in
16 every incidence. They cannot -- they can withhold
17 CPR if there is an DNR in place. That same rule
18 applies for hospice residents in that personal care
19 facility as well as for any other.

20 A call to the hospice agency is also
21 required. However, this does not take place -- the
22 place of the home's call to the EMTs. The hospice
23 agency may choose to give alternate directions to
24 the EMTs, but the home is not qualified or
25 permitted to not call the EMTs.

1 And I must tell you it is the EMT's
2 discretion whether they are going to accept what
3 hospice is telling them as an alternate choice.
4 More times than not the EMTs will transport that
5 person who has ceased to breathe based on their --
6 the -- the direction they're given from their
7 command.

8 But I have to tell you the majority of
9 times those patients are transported, having ceased
10 to breathe, are transported to an emergency room
11 for pronouncement rather than wait for the hospice
12 nurse to get there.

13 A call to -- in accordance with state
14 law, 35 Pennsylvania Statute 450.507, a registered
15 nurse is legally permitted to assess life signs and
16 pronounce death. Therefore, if an RN or a
17 physician pronounces the death of a resident, EMTs
18 do not need to be called. This applies to hospice,
19 as well as in all personal care homes.

20 This practices leads to a tremendous
21 amount of confusion and anxiety for the patient and
22 their families. Hospice personnel have been
23 instructed to work directly with each EMT unit to
24 create a process to address this issue on a
25 patient-by-patient basis rather than having it

1 addressed in the personal home care guidelines.

2 This is another example where better
3 coordination of care focused on the patient could
4 help Pennsylvania reach a goal of better quality
5 end-of-life care.

6 Thank you for this opportunity to share
7 my insights on just a few opportunities available
8 in Pennsylvania to better coordinate care between
9 providers for the benefit of all Pennsylvanians.

10 And I would be happy to answer any
11 questions.

12 CHAIRMAN MUNDY: Thank you very much for
13 your testimony.

14 I must say I -- as I read what you just
15 read about the EMTs responding or -- or needing to
16 be called, I am really confused.

17 Obviously, I don't do this for a living
18 and you do. So maybe you could walk me through
19 this again.

20 The home must call an EMT in every
21 incidence; but then later on, in -- in accordance
22 with state law, a registered nurse is legally
23 permitted to assess signs of life and pronounce
24 death and EMTs do not need to be called. What?

25 DIRECTOR GERHART: EMTs do not need to

1 be called for hospice patients when they are
2 residing in their own homes or any time, quite
3 honestly.

4 However --

5 CHAIRMAN MUNDY: So in a personal care
6 home they do need to be called?

7 DIRECTOR GERHART: Correct.

8 CHAIRMAN MUNDY: Each and every time?

9 DIRECTOR GERHART: That's correct.
10 That's based on the rules and regulations of the
11 personal care home.

12 CHAIRMAN MUNDY: Even when -- even when a
13 hospice nurse might be on site?

14 DIRECTOR GERHART: Yes. That's correct.

15 CHAIRMAN MUNDY: I see.

16 DIRECTOR GERHART: That is correct. They
17 must be called.

18 CHAIRMAN MUNDY: Okay.

19 DIRECTOR GERHART: And in --

20 CHAIRMAN MUNDY: Now I understand.

21 DIRECTOR GERHART: And in some cases, as
22 I said, we've been able successfully to negotiate,
23 if you will, an understanding with -- with certain
24 EMT units who will go, because they have to
25 respond, they've gotten the call, but they'll sit

1 and wait for us to get there rather than
2 transport.

3 But the majority of them, as I said,
4 will -- they go, they've called, they must go, and
5 they -- they follow the command given to them back
6 at their hospital-based unit, and for the most part
7 it is transporting that patient who has ceased to
8 breathe back to the ER for pronouncement.

9 CHAIRMAN MUNDY: It doesn't make a lot of
10 sense, huh? And it's expensive.

11 DIRECTOR GERHART: Yes. That expense is
12 then transferred to the patient's family because it
13 is -- it's not something that's picked up by
14 insurance. It's paid by the -- I mean the same as
15 anything in personal care homes, it's paid for by
16 family.

17 CHAIRMAN MUNDY: I see. Interesting.

18 DIRECTOR GERHART: And sad.

19 CHAIRMAN MUNDY: Representative
20 Samuelson.

21 REPRESENTATIVE SAMUELSON: Thank you. I
22 had another meeting so I'm not sure if Secretary
23 Hall covered this earlier.

24 But I guess my question is for Secretary
25 Hall. The issue that's raised about people on the

1 hospice benefit also getting aging waiver services
2 and whether there's restrictions that need to be
3 addressed.

4 SECRETARY HALL: Excuse me. Are you
5 going to answer that?

6 DIRECTOR GERHART: Okay.

7 REPRESENTATIVE SAMUELSON: Have you
8 addressed that?

9 CHAIRMAN MUNDY: Well, we can talk about
10 it again. Go ahead.

11 DIRECTOR GERHART: That -- I'm sorry. Do
12 you want to --

13 REPRESENTATIVE SAMUELSON: I'm told you
14 might have already covered this. Sorry about that.

15 DIRECTOR GERHART: Yes.

16 SECRETARY HALL: Well, I think -- I think
17 what Susan just referred to in her testimony is
18 that we issued a draft policy to remove that
19 barrier and to have those programs compliment each
20 other, and it's out for comments with stakeholders
21 right now.

22 We -- that will come back in and then we
23 intend to fix that problem by issuing a final
24 policy.

25 REPRESENTATIVE SAMUELSON: The proposal

1 from July then?

2 SECRETARY HALL: Yes.

3 REPRESENTATIVE SAMUELSON: Okay.

4 SECRETARY HALL: That's correct.

5 REPRESENTATIVE SAMUELSON: Okay. Thank
6 you.

7 CHAIRMAN MUNDY: Under what --

8 DIRECTOR GERHART: And that is what we
9 are urging speedy -- speedy resolution to. Because
10 that is a much needed coordination of care for
11 the -- Pennsylvanians.

12 CHAIRMAN MUNDY: As someone who helped
13 draft this report -- this report and
14 recommendations, can you point to things that the
15 legislature might help with?

16 Again, as I mentioned earlier, I only see
17 two specific recommendations for the Pennsylvania
18 legislature.

19 But are there other things in here with
20 regard to hospice services that you think might be
21 moved further along with legislative -- maybe just
22 recommendations or -- or greater awareness,
23 promoting awareness as opposed to legislation or
24 regulation?

25 DIRECTOR GERHART: I would agree. And I

1 agree with Dr. Straton, what he said this morning.
2 To put -- you know, this is more than just a
3 medical issue.

4 This is an issue for all of us in the --
5 in the Commonwealth, and the more that we can get
6 public awareness out there and get people talking
7 about it, the -- the better off we're going to be
8 to get people to not be afraid of it and to make
9 decisions when they are able to make decisions. At
10 least verbalize what they would -- what they would
11 want should this happen to them or should they be
12 faced with decisions like you said, to have -- have
13 your -- your someone know what you would want, you
14 know, to take place, should you get hit by a car
15 today or should you be diagnosed with metastatic
16 cancer.

17 I -- I do think -- it's everything.
18 It's -- it's the medical community. It's
19 legislators. It's activists. It's every one of
20 us.

21 We have the responsibility as a citizen
22 of this Commonwealth to -- to broaden access and
23 awareness. And the more that you -- you have your
24 constituents that -- you know, you've got a
25 broad -- broad base of constituency that you could

1 speak to, provide information, even -- even give
2 them our information, our resource, the
3 Pennsylvania Homecare Association, to numbers and
4 names to call for information to present as
5 resources.

6 CHAIRMAN MUNDY: Other questions from
7 committee members?

8 Ms. Gerhart, thank you so much for your
9 patience with us.

10 DIRECTOR GERHART: Thank you.

11 CHAIRMAN MUNDY: And for being here
12 today.

13 DIRECTOR GERHART: You're welcome. Thank
14 you.

15 CHAIRMAN MUNDY: And we look forward
16 to -- I don't know. Maybe the task force is not --
17 is not necessary. Only had one taker so far.
18 That's two.

19 Maybe -- maybe -- I think -- I do think
20 that we should get together, those of us who are
21 interested, in kind of hashing out some of these
22 issues and deciding whether -- whether there is any
23 action we as a committee can take to further
24 this -- this discussion.

25 So with that said, I appreciate your

1 attendance here, members, and thank you so much to
2 our testifiers.

3 Meeting adjourned.

4 (The proceedings were concluded at
5 11:43 p.m.)

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I hereby certify that the proceedings and evidence are contained fully and accurately in the notes taken by me on the within proceedings and that this is a correct transcript of the same.

Brenda S. Hamilton, RPR
Reporter - Notary Public