

Centers for Medicare & Medicaid Services  
Special Open Door Forum:  
Medicare Coverage of Kidney Disease Patient Education Services

Thursday, November 6, 2008  
2:00 PM – 3:30 PM Eastern Time  
(Conference Call Only)

The Centers for Medicare and Medicaid Services (CMS) will host a Special Open Door Forum to discuss Section 152(b) of the Medicare Improvements for Patients and Providers Act of 2008 (Public Law 110-275), which provides coverage for Kidney Disease Patient Education Services for individuals with Stage IV chronic kidney disease (CKD). The forum will be held via audio-conference on November 6, 2008 at 2:00 PM – 3:30 PM Eastern Time.

These services are designed to provide individuals with comprehensive information on:

- the management of comorbidities (including for purposes of delaying the need for dialysis);
- prevention of uremic complications;
- each available option for renal replacement therapy (including hemodialysis and peritoneal dialysis at home and in-center as well as vascular access options) and kidney transplantation.
- the opportunity to actively participate in the choice of therapies and provide information tailored to individual patient needs.

We are most interested in comments regarding the following topics.

- What are the specific competencies that the clinician referring the patient for kidney disease patient education services and the qualified individual providing the education services should possess?
- What are the accepted clinical criteria (or standards of practice) for diagnosing someone with Stage IV chronic kidney disease (CKD)?
- What kind of information does a patient need in order to make an informed decision regarding the available dialysis, vascular access, and kidney transplant options?
- What additional clinically appropriate topics should be discussed with the patient (for example: dietary/fluid restrictions)?
- What are the different modalities of education (for example: web, group session) appropriate for kidney disease patient education services?
- What are the existing chronic kidney disease education resources that are publicly available? In addition to the resources, please provide information regarding sponsorship or funding provided to produce the existing education programs.

We look forward to your participation.

Special Open Door Forum Participation Instructions:

Dial In: 1-800-837-1935

Reference Conference ID: 70344910

Note: TTY Communications Relay Services are available for the Hearing Impaired. For TTY services dial 7-1-1 or 1-800-855-2880 and for Internet Relay services click here <http://www.consumer.att.com/relay/which/index.html> . A Relay Communications Assistant will help.

An audio recording of this Special Forum will be posted to the Special Open Door Forum website at [http://www.cms.hhs.gov/OpenDoorForums/05\\_ODF\\_SpecialODF.asp](http://www.cms.hhs.gov/OpenDoorForums/05_ODF_SpecialODF.asp) and will be accessible for downloading beginning November 14, 2008.

For automatic emails of Open Door Forum schedule updates (E-Mailing list subscriptions) and to view Frequently Asked Questions please visit our website at <http://www.cms.hhs.gov/opendoorforums/>

Thank you for your interest in CMS Open Door Forums.

Audio File for this Transcript:

[http://media.cms.hhs.gov/audio/SpcFrmODF\\_ESRDMIPPA.mp3](http://media.cms.hhs.gov/audio/SpcFrmODF_ESRDMIPPA.mp3)

**CENTERS FOR MEDICARE AND MEDICAID SERVICES**  
**Special Open Door Forum:**  
**Medicare Coverage of Kidney Disease Patient Education Services**

**Moderator: Natalie Highsmith**  
**Conference Leader: Jamie Hermansen**  
**November 6, 2008**  
**2:00 pm ET**

Operator: Good afternoon. My name is (Amanda) and I will be your conference facilitator today.

At this time, I would like to welcome everyone to the Centers for Medicare and Medicaid Services Special Open Door Forum on Medicare Coverage of Kidney Disease Patient Education Services.

All lines have been placed on mute to prevent any background noise. After the speaker's remarks, there will be a question and answer session.

If you would like to ask a question during this time, simply press star, the number one on your telephone keypad. If you would like to withdraw your question, press the pound key.

Thank you Ms. Natalie Highsmith, you may begin your conference.

Natalie Highsmith: Thank you (Amanda) and good day to everyone and thank you for joining us for this Special Open Door Forum

Today CMS we'll discuss Section 152B of the Medicare Improvements for Patients and Providers Act, also called MIPPA of 2008, which provides coverage for kidney disease patient education services, individuals with stage four chronic kidney disease.

These educational services will provide individuals with comprehensive information and I will turn the call over to (Jamie Hermanson) who works in our Division of Medical and Surgical Services in our Coverage and Analysis Group and our Office of Clinical Standards and Quality to review those.

(Jamie)?

(Jamie Hermanson): Thank you Natalie. We want to - we thank everyone for taking the time out of your busy schedules to come and join us for the Special Open Door Forum.

These services are designed to provide individuals with stage four chronic kidney disease and provide them comprehensive information on the management of co-morbidities, including further purposes of delaying the need for dialysis, prevention of your uremic complications, each available option for renal placement therapy, including chemo-dialysis, peritoneal dialysis, both actual and infinite dialysis options, vascular access options and kidney transplantation options.

It - they're also designed to provide individuals with the opportunity to actively participate in the choice of therapies and provide information tailored to individual patient needs.

Based on the topical lists below, which was provided in the Special Open Door Forum Announcement, we plan to spend approximately ten minutes per topic receiving your feedback. We have dedicated - we have a dedicated email box for this topic for follow-up purposes.

The email address is ckdeducation@cms.hhs.gov. It's c as in cat, k as in kangaroo, d as in dog, education@cms.hhs.gov. Now I would like to hand back to Natalie Highsmith and we can begin with our first questions.

Natalie Highsmith: Thank you (Jamie). Our first question that we would like feedback on is, "What are the specific competencies that the clinician referring the patient for kidney patient disease education services and the qualified individual providing the education services should possess?"

(Amanda) if you could just remind everyone on how to get into the queue to ask - to give their feedback on this question and everyone please remember when it is your turn, to restate your name, the state you are calling from, what provider or organization you are representing today, and please remember we are allowing ten minutes responses for this first question. (Amanda)?

Operator: At this time, as a reminder, if you wish to ask a question, please press star and the number one on your telephone keypad.

We'll pause for just a moment to compile the Q&A Roster.

There is currently nobody in queue at this time.

Natalie Highsmith: Okay. Well we can ahead and move to question number two, which is, "What are the accepted clinical criteria or standards of

practice for diagnosing someone with stage four chronic kidney disease?”

We’re taking feedback on question number two.

Operator: Once again, as a reminder, if you wish to ask a question, please press star and then one.

The first question is from (Joyce Jackson).

(Joyce Jackson): Yes, this is (Joyce Jackson) calling from Washington State, Northwest Kidney Centers. I’m sorry I didn’t know how to do this, so I do want to comment on the first question as well.

The specific competencies that the clinician referring the patient for CKD education, it should be a nephrologist. And we would say non-physician practitioners should not be able to make a referral for this service.

What are specific competencies that the qualified individual providing the education service should possess? We would say it should be a Board Certified or Board Eligible Nephrologist or as in the law, Physician Assistant, Nurse Practitioner or Clinical Nurse Specialist who are working under the supervision of a Nephrologist for at least 12 consecutive months within the last five years and who have an understanding of the required curriculum, including exposure to all forms of dialysis.

Finally, we would say that, although the law did not recognize this, a Certified Nephrology Nurse, a CNN, who is an RN with - who’s passed the national examination and has worked for two years in

dialysis, should be added as a qualified individual to provide the education.

Natalie Highsmith: Thank you.

Operator: Thank you. The next person in queue is (Deb Williams). Your line is now open.

(Deb Williams): Hi. I'm also going to comment on number one, because I also like (Joyce) had a little difficulty going on.

The way the law is written, it's a physician or practitioner service, we believe a physician component is very important and key in fact, that is a physician, non-physician practitioner, to define the need for dialysis, which is good for the patient and good for the program.

We do think that it could be provided in a physician's office by an RN under the physician's supervision. But the physician has to be very involved.

Natalie Highsmith: Thank you.

Operator: Thank you. The next person - the next question in queue is from (Delores Penia). Your line is now open.

(Delores Penia): Yes, this is (Delores). I'm from (Ocacu) Care and Kidney Group and you asked about the accepted clinical criteria and in our practice they use the (DOCI) guidelines and, which is a GFR of 16 through 30.

Natalie Highsmith: Thank you.

Operator: Thank you. The next question is from (Keith Listler) from Massachusetts. Your line is now open.

(Keith Lester): This is (Keith Lester) from Fresenius Medical Services and not to be duplicative, but I agree with (Joyce) and (Delores) as far as the qualifications and the competencies and as far as the NKF standards for stage four GFR less than 300 cc's for the accepted clinical criteria.

Natalie Highsmith: Thank you.

Operator: Thank you. The next question is from (Leanna Tistler). Your line is now open from Washington.

(Leanna Tistler): I just wanted to add to the previous speakers. As far as the criteria, I think the key (DOCI) clearly defines chronic kidney disease which is a syndrome and EGFR is just one of the indicators to define chronic kidney disease, so it's important to take into consideration symptoms and signs that some patients may have and decide the EGFR.

In addition, I think sometimes patients end up in stage five CKF, and they still need to be eligible to receive pre-dialysis education, if they haven't received so in stage five - I mean, in stage four previously.

Thank you.

Natalie Highsmith: Could you tell me which organization you're with?

(Leanne Tistler): I'm a Nephrologist from the Northwest Kidney Centers in Seattle, Washington.

Natalie Highsmith: Thank you.



Operator: Thank you. The next question in queue is (Kathleen O'Keefe) from Massachusetts. Your line is now open. (Kathleen) your line is now open. Your phone may be on mute.

(Kathleen Smith): Thank you very much. This is (Kathleen Smith) with Fresenius Medical Care. I'm here with (Kathleen O'Keefe). I just wanted to add to the earlier comments. Since it's a patient in stage four and one of the issues in our discussion of this provision of the law, was the need to get patients referred to a nephrologist earlier, it may be that diverticologist, endocrinologists, cardiologists, family practitioners would also be appropriate to identify and refer a patient for preparation for dialysis and these education sessions.

Natalie Highsmith: Thank you very much (Kathleen) for your comments. Next please.

Operator: The next question is queue is (Lea Beard). Your line is now open from Arizona.

(Jennifer Casey): Hi actually, my name is (Jennifer Casey). And I am with (Lea Beard). I'm calling from the Southwest Kidney Institute in Tempe, Arizona.

My comment is regarding the qualified individual providing the education services. I am a Masters Preferred Social Worker and I current work under the care of 30 physicians at the Southwest Kidney Institute and I provide all education services currently regarding vascular options as well as managing co-morbid and providing dialysis and transplantation options.

Natalie Highsmith: Can you provide us with some details on - you're indicating you wanted to provide feedback on the clinicians. Are you...?

(Jennifer Casey): Sure. Yes. My comment is that because - I wanted to also put out there that Masters Level Social Workers are also qualified to be able to provide education, especially if they have experience in nephrology.

Natalie Highsmith: Thank you.

Operator: Thank you. The next question's from (Joyce Jackson) from Washington. Your line is not open.

(Joyce Jackson): Yes, I'm sorry. I forgot to say under the first question of the qualifications of the individual referring the patient for kidney disease, I had recommended a nephrologist because they're the - they're really the only ones to determine if someone is eligible for dialysis.

But I would like to suggest an exception for rural areas where no nephrologist is based in the community and in this case, the referring clinician may be a primary care physician, internal medicine or family practice or a specialist as (Kathleen Smith) referenced a cardiologist or endocrinologist.

But in general, I think the law should really encourage the referral to this education to come from nephrologist.

Thank you.

Natalie Highsmith: Thank you for your additional comments.

Operator: Thank you. The next question in queue is (Sheila Winer) from New York. Your line is now open.

(Sheila Winer): Thank you very much. This is (Sheila Winer) with the National Kidney Foundation. And I have a question about the first item regarding who's qualified to provide the education and since my understanding is that the law stipulates who that would be specifically a physician or an advanced nurse specialists and nurse practitioner, is that open to interpretation?

And I guess my question is, could some other professional individual who has the qualifications to provide such education, for example the social worker who spoke previously, would they be able to considered for providing this education under the way the law is currently written?

Natalie Highsmith: Thank you for your question. At this time, at this session, we are looking for feedback and we're not able to answer questions at this time. But we do appreciate it.

(Sheila Winer): Okay, thank you.

Natalie Highsmith: You're welcome.

Operator: Thank you. The next question in queue is from (Deb Williams) from Maryland. Your line is now open.

(Deb Williams): Thank you. One comment on the law as I read it, is that it's very clear to people who can bill under the physician's fee schedule and it's a very specific the physician's and non-physician practitioners that can do it. However, it would - we recommend that CMS allow social workers, when appropriate, certified dietitians, when appropriate to be able to bill, excuse me, to be able to provide the service, when appropriate in the physician's office.

Natalie Highsmith: Thank you. Next caller please.

Operator: At this time, nobody else is in queue, but as a reminder, please press star and one to ask a question.

The next person in queue is (Dean Esterman) from Montana. Your line is now open.

(Dean Esterman): Thank you very much. I work for the Quality Improvement Organization in Montana. And just as a reminder, our state stretches from the equivalent of Chicago to Washington, D.C. and in that area we have nine nephrologists.

So limiting this to nephrologists in a very rural state would be totally inappropriate. We must have other providers who are adequately educated and trained about the nuances of chronic kidney disease and end stage renal disease, otherwise in rural state we'll continue to have people show up in stage five chronic kidney failure in the emergency room for immediate dialysis without any opportunity for education.

So please consider the rural and sparsely populated areas. Thank you.

Natalie Highsmith: Thank you. (Amanda) we have reached our ten minute allotment for our question number two, so now we will move onto question number three, which is, "What kind of information does a patient need in order to make an informed decision regarding the available dialysis, vascular access, and kidney transplant options?" We're taking feedback on question number three.

Operator: Thank you. As a reminder, to ask a question, please press star, and then one, on your telephone keypad.

Natalie Highsmith: And may I...

Operator: The first question...

Natalie Highsmith: I'm sorry. May I just remind everyone, that we will, time allowing, we will have a general Q&A at the end after we ask - after we get feedback on all six questions, we will have a general Q&A at the end. So please, everyone, please stick to the question that we have asked at this time.

Operator: Thank you. The first question in queue is (Sally Rice) from Kentucky. Your line is now open.

(Sally Rice): Yes, thank you. I would like to point out that in my experience with pre-dialysis education, adjusting to their lifestyle and understanding what lifestyle changes they need to make, is a very important part and the social worker does play a very important role of that, as well as the dietitian and so, allowing anyone who would be part of the dialysis team, as in the conditions of coverage and working as a team seems very appropriate for giving the kind of knowledge required by the patient. Thank you.

Natalie Highsmith: Thank you.

Operator: Thank you. The next question in queue is from (Lisa Ferris) from Alabama. Your line is now open.

(Lisa Ferris): Thank you so much. Yes, I'm (Lisa Ferris) and I'm Nurse Practitioner at the University of Alabama in nephrology, also a member of the NKF Counsel for Advanced Practitioners.

And in response to this question, I simply want to say that we certainly feel strongly that the curriculum that is offered to the patients, and I'm sure we'll be hearing more about content for that, needs to be a unified, organized curriculum that is not individualized by regions across the country, that we have kind of a structured program that we follow and that we offer for patients, so we can get some type of equality measurement of what patients have been instructed and/or exposed to.

So the one thing that we were certainly very interested in having as far as council from, of course, NKF and here at University of Alabama, was being sure that what curriculum was offered in New York was covering the same topics that we were addressing here in Birmingham and California, etc.

So we have some way of measuring, you know, exactly what patients were being instructed and taught. That was one thing that we were very interested in having.

Natalie Highsmith: Thank you so much for your feedback.

Operator: Thank you. The next question in queue is (Tracy Fortson) from New York. Your line is now open.

(Tracy Fortson): Hi. I just wanted to stress that information that's provided to the patients should - and reiterating what the previous commenter said, it should be concise, so that everybody is receiving the same information

and also the information should be objective in terms of not necessarily influencing the patient to one treatment option over others and also to be sure that it's clear cut and patient friendly, so that the information is not so clinical that it makes difficult for the patients to understand what their options are.

Natalie Highsmith: Thank you (Tracy). Which organization are you with?

(Tracy Fortson): The National Kidney Foundation, sorry.

Natalie Highsmith: Thank you.

(Tracy Fortson): I'm with the National Kidney Foundation. I was having a little trouble with the star and one trying to get through to get my question out or my comments out, but it worked okay.

Natalie Highsmith: Thank you.

Operator: Thank you. The next question in queue is from (Mary Churchill) from Nebraska. Your line is now open.

(Mary Churchill): Yes, this is (Mary Churchill) and I'm an nephrology nurse practitioner with Lincoln Nephrology Group. And we do have a patient education program provided through one of our dialysis centers and it's very good at just providing information for peritoneal hemo, transplants, insurance, issues for the social worker, and dietary.

And in observing the patients that go through that versus the ones that don't - they're - the patients that go through the program are just much better acclimated and prepared and the stress level is really better on those patients.

So it's objective and I think it's a very good beneficial thing to do.

Natalie Highsmith: Thank you so much for your feedback.

Operator: Thank you. The next question in queue is (Terry Brown) from South Carolina. Your line is now open.

(Terry Brown): Hi, this is (Terry Brown) and I'm an assistant professor at the University of South Carolina along with the National Chairperson of the Council of Nephrology Social Workers.

I have two comments. Number one, I think it's important that, in addition to dialysis, vascular access and kidney transplant options, we need to make sure that we're addressing the treatment option of no treatment, so that we're educating patients that they have the right to refuse treatment and that no treatment is a treatment option.

And like some of my colleagues have already chimed in, I think it's also critical that we include psychosocial information in this educational component, specifically looking at adjustment, coping, work, insurance, exercise, rehabilitation. Thank you.

Natalie Highsmith: Thank you very much.

Operator: Thank you. The next question in queue is from (Leanna Tistler) from Washington. Your line is now open.

(Leanna Tistler): I just wanted to add to the previous speakers. It's important to provide evidence based information and to really give patients a complete picture and I think it's not enough just to talk about modalities in



general. We have to give them survival data and we have to be very complete as far as there are seven modalities available to all patients and it's not enough just to say home modalities or home hemo modalities.

We need to specify it. We need to tell them what is the survival difference and what is the difference in quality of life when we describe modalities.

And it should be patient centered, so it should always start where the patient is, before proceeding any further. But I do think it should be a balance between competent medical information and appropriateness at the patient level. Thank you.

Natalie Highsmith: Can you repeat where you're - which organization you're with and your name please?

(Leanna Tistler): I'm a nephrologist, (Leanna Tistler) at the Northwest Kidney Centers in Seattle, Washington.

Natalie Highsmith: Thank you.

Operator: Thank you. The next question in queue is from (Celeste Castrioloe) from North Carolina. Your line is now open.

(Celeste Castrioloe): Hi. Thank you very much. I'm actually the chair person for the Patient Family Counsel for the National Kidney Foundation. And I just wanted to talk about the - I agree with what everyone has said is regarding consistent and comprehensive type of education provided to patients.

We also believe that the comprehensive should deal with all modalities and not only in dialysis, but the various different versions of home dialysis, hemo dialysis. And also, talking about a fair and balanced way of presenting this information to the patients, because sometimes there can be some folks leaning a little towards one or a hospital system or hospital favoring one type of dialysis over another and I think this needs to be communicated in a very unbiased way.

And also not making an assumption, whether or not, a patient will be eligible to do a certain type of modality, I think that's crucial, because a patient can learn what the modality is, what they might need to do to improve their outcomes on that modality.

Because right now, patients aren't getting any education on this or very little to make a real informed choice.

I mean, you know, I've said dialysis yes I do patients since I was 17 and I'm 43, and I've had to learn it all along the way, so I think this is crucial to having an empowered healthy population.

Thanks so much.

Natalie Highsmith: Thank you so much for your feedback. We really appreciate it.

Operator: Thank you. The next question in queue is from (Doreen Chatrell) from Wisconsin. Your line is now open.

(Doreen Chatrell): Hi, yes. I'm from the Medical Education Institute. I wanted to echo what several people said about the importance of modality and lifestyle about not having geographic variations in what patients are

presented with and in keeping the information evidence based and specifically providing quality of life and survival information.

In terms of specific information, we think that it's important to include content on how to prolong kidney failure like people on diabetes and hypertension and other co-morbidities, following healthy lifestyles, avoiding nephro-toxic agents, and then further by - we really, really believe that it's critically important to include information on how to live a good life with kidney disease.

And most importantly, I think maybe to make the point up front that it is possible to have a good life with kidney disease so that the rest of the information will actually be taken in by the patient.

We think it's important also to have an overview of your role as an active self manager. This is something that most patients are not necessarily aware of. They need to be.

And then the impact as someone else said, of treatment choice on maintaining employment, on the cost of care and the coverage of treatment, on the diet and fluid and the numbers of medications and symptom numbers and severity and emotional adjustment, sexuality and fertility, which can be very important to some of the younger patients, hospital days and also mortality risks.

And transplant information needs to include some of the variations on transplant, like parrot exchange and kidney pancreas transplant for people with type one, preemptive transplant and such.

So that's what I wanted to add.

Natalie Highsmith: Thank you so much. And (Amanda) we have time for one final person for feedback please.

Operator: Okay. The next person is (Delores Pena) from Florida. Your line is now open.

(Delores Pena): Hi this (Delores) again. I'm from (Ocala) Kidney Group. I'm a licensed clinical social worker. Just two quick comments. One thing that I haven't heard is the education about the importance of quitting smoking if they are smoking, particularly for people are considering transplants, but also because there's a cardiovascular risk.

And the other comment that I'd like to make, is that given the range of topics that people have put forth as needing to be covered, I think it's even more important to have a team approach to it.

We have done kidney education in our area for the last ten years and we've gradually revised our program. But the one thing that we've always done, is use a team approach which includes the nephrologist, a nurse, a dietitian and a social worker because the range of topics is so broad.

So that's my two cents.

Natalie Highsmith: Thank you. Now we will take our feedback on question number four, which is, "What additional clinically appropriate topics should be discussed with the patient? For example, dietary or fluid restrictions. We will take comments on question number four.

Operator: This is a reminder, to ask a question, please press star, and then one, on your telephone keypad.

The first person in queue is (Karen Wisen) from Missouri. Your line is now open.

(Karen Wisen): Yes. I'm calling as chair elect of the Council on Renal Nutrition for the National Kidney Foundation and I'm a Renal Dietitian at Washington University School of Medicine.

And as far as what additional education should be provided, we really feel that the nutrition component should not duplicate the current Medical Nutrition Therapy Acts that were passed in 2002. And this provides for referral, assessment and counseling by a registered dietitian once the GFR falls under 50.

And we really think patients at this stage should be steered towards using the MNT benefit to which they're referred to by a physician.

And that's all I would have to say about that. Thank you.

Natalie Highsmith: Thank you.

Operator: Thank you. The next question in queue is from (Keith Lester) from Massachusetts. Your line is now open.

(Keith Lester): Again, this is (Keith Lester) from Fresenius Medical Services. Not only to the dietary and fluid restrictions but also to include medications, compliance, social services support. As many of these patients get into stage three, stage four, they - obviously we need to make sure that they understand what they're - what the impact financially can be on them if they actually do become a dialysis patient.

And also then, of course, diet and exercise how that can help, and hopefully, prolong their necessity to go onto dialysis.

Natalie Highsmith: Thank you.

Operator: Thank you. The next question in queue is from (Laura Gamba) from Florida. Your line is now open.

(Lisa Hall): Hi this is actually (Lisa Hall). I work with (Laura Gamba) who's with the Florida QIO and I'm with the Florida ESRD Network and also the Council of Nephrology Social Workers Executive Committee.

Vocational rehab is - should be a primary content in this program, because if folks that don't have insurance aren't going to be able to follow-up on any of the CKD education in the other clinical areas and people who work are obviously less depressed, have better social opportunities, fewer barriers to health care including transplants, higher income and insurance coverage.

And of course, this quality of life can affect outcomes in dialysis.

Natalie Highsmith: Thank you.

Operator: Thank you. The next question in queue is from (Leanna Tistler) from Washington. Your line is now open.

(Leanna Tistler): I think the patient should know that most patients with kidney disease do not die from kidney failure, they die from cardiovascular complications and it's number of all patients. And so I think, all the co-morbidities should be presented in a way of how could treat the

kidney to save the heart? And that includes management of fluids, hypertension, anemia, phosphorous and calcium, vitamin D management, depression, because they all relate ultimately to their survival and that's a cardiovascular survival.

And that's the context that I feel strongly how the co-morbidities should be presented in the educational format.

Natalie Highsmith: Thank you.

Operator: Thank you. The next question in queue is from (Lisa August) from Kentucky. Your line is now open.

(Lisa August): I just wanted to mention that I think this sounds really kind of basic, but I've taught an options class for several years here in Kentucky. I'm with the National Kidney Foundation of Kentucky, and I think I've found that one of the most helpful things to help people - patients understand kidney disease is to talk about the function of the kidney in relation to the symptoms they have.

I think it helps them understand how the treatment works better. And most importantly, why it's important for them to consider a treatment or not.

Natalie Highsmith: Thank you.

Operator: Thank you. There is no one else in queue. But this is a reminder, to ask a question, please press star and then one on your telephone keypad.

The next question in queue is from (Karen Wisen) from Missouri. Your line is now open.

(Karen Wisen): Yes, this is (Karen Wisen) again calling on behalf of the Council of Renal Nutrition. I think one of the things we need to remember is, that if we can get these patients referred and utilizing the Medical Nutrition Therapy Act, that the qualified registered dietitian will be doing a full assessment of the patient, along with all their co-morbidities based on the medical information from the physician and be able to cover a broad range of counseling services with these patients, whether they're just kidney disease or kidney disease and diabetes.

So that's why I think really trying not to duplicate those benefits, but getting them individually referred as part of that educational component is very, very important. Thank you.

Natalie Highsmith: Thank you.

Operator: Thank you. The next question in queue is from (Lea Beard) from Arizona. Your line is now open.

(Lea Beard): Yes, this is (Lea Beard) and I'm a Renal Dietitian at Southwest Kidney Institute in Tempe, Arizona.

And I work for a multidisciplinary - I work with a multidisciplinary team including myself as a dietitian, nephrologist, social worker, and we've been doing this program for many years and that the patient goes to see the nephrologist and then is referred to both social work for education on modality, or if they're having trouble just accepting the fact that they have a disease and then coming by myself as the dietitian.



Typically, we start seeing patients at stage three, where we seem to be able to do the most help. And being able to help those patients, not only with the renal component from a dietary standpoint, but with cholesterol, with weight loss, especially if they're looking to go to transplant and being able to cover all the areas that - all the other commenters have spoken about.

There's so many different areas about smoking cessation, that I agree with the depression and there's just a lot of areas that could be helped that we aren't allowed to do with our patients at this time.

Natalie Highsmith: Thank you.

Operator: Thank you. The next question in queue is from (Mary Churchill) from Nebraska. Your line is now open.

(Mary Churchill): (Mary Churchill) again from Lincoln Nebraska and nephrology - nurse practitioner with - I'd like to just support the thoughts that the pre-education for these patients (unintelligible) and just what kidney status is and the types of issues that they're going to get into when they get on dialysis, like having to take things for bone and mineral status and anemia is important and something we need to do.

I also would like to add that we need to discuss accesses for whether PD or hemo and that those accesses have problems and they need continuing maintenance on them and so that's not such a surprise and frustration to patients as they get onto dialysis and go through the process.

So I just wanted to make sure that we would add that.

Natalie Highsmith: Thank you.

Operator: Thank you. There are no other questions in queue at this time.

Natalie Highsmith: Okay we can go ahead and move to our question number five, which is, “What are the different modalities of education, for example Web or a group session that is appropriate for kidney disease patient education services?”

We’re taking feedback on question number five please.

Operator: This is a reminder, to ask a question, please press star, and then a one.

The first question in queue is from (Joyce Jackson) from Washington. Your line is now open.

(Joyce Jackson): Thank you. This is (Joyce Jackson) from Northwest Kidney Centers. Well, certainly we would support the individual face to face encounter as a primary form for education. As well, face to face group sessions should be allowed and we would say up to five patients with an accompanying support person, caregiver, etc encouraged to attend.

From a tele-health prospective, if it’s face to face on the individual level with a camera and voice, that we believe should be allowed, especially recognizing the rural comments made earlier.

Finally, we would not recommend Web education as meeting the criteria for this benefit or written material review or telephone. We really believe face is face is crucial.

Thank you.

Natalie Highsmith: Thank you.

Operator: Thank you. The next question in queue is from (Keith Lister) from Massachusetts. Your line is now open.

(Keith Lister): Again, this is (Keith Lister) from Fresenius Medical Services. I agree with (Joyce) that face to face is obviously crucial. The group sessions that we have in our treatment options program across the entire U.S. have been very successful and not only providing the education to the patients, but also putting them in contact with other patients that are also living with the potential actually of becoming a dialysis patient.

So I think the face to face or the group would be the ideal.

Natalie Highsmith: Thank you.

Operator: Thank you. The next question in queue is from (Lisa Ferris) from Alabama. Your line is now open.

(Lisa Ferris): Thank you so much. Yes, I'm from the University of Alabama again. I concur with what has just been mentioned. The one thing that we add here in our program is that we do an individual assessment for learning needs and learning style before the patient is integrated into one of our programs.

We also have face to face. We have group classes, but they're structured based on the patient's learning style and preferred learning modality or type of learning style.

We think this is very important. In our face to face classes, whether or not, that's class or individual instruction, patients leave the class with supportive documentation. Some patients prefer higher tech media. Some patients prefer written information, so we try to tailor and have a variety of materials that support the patient's learning style and I think that's very important.

I don't think - I think the program that is offered nationwide needs to have a component of assessment of learning style, because many of these patients, even if they are late stage four, they're uremia is such that they're comprehension of information is just impaired.

An earlier stage four patient may not be as impaired in their learning, you know, as far as absorbing information. So I think one of the things that's important is to be sure that there's an assessment of how the patient learns optimally. Thank you.

Natalie Highsmith: Thank you.

Operator: Thank you. The next question in queue is from (Lea Beard) from Arizona. Your line is now open.

(Jennifer Casey): Hi this (Jennifer Casey) social worker at the Southwest Kidney Institute in Arizona. I just want to offer my support as to the type of teaching. I do believe that the couple years that the Southwest Kidney Institute has done their CKV education program, we've done it out of the doctor's offices and we've done one on one. The one on one sessions have proven to be more - the patients just tend to choose the modality a little bit quicker and start planning for access sooner than do the group sessions, because they have the one on one support.

I do believe that a group should be allowed and I do agree with literature should be given to the patient as well as the high technology such as the different Web sites and so forth to add to their learning.

Thank you.

Natalie Highsmith: Thank you.

Operator: Thank you. The next question in queue is from (Leanna Tistler) from Washington. Your line is now open.

(Leanna Tistler): Yes, (Leanna Tistler) from the Northwest Kidney Centers. I think dialysis education or kidney failure education or CKD education is a time consuming process. And I think it's very important when you introduce reimbursable service to specify that the delivery should be based on face to face contact versus other possibilities.

Whatever the appropriate time is, whether it's 60 minutes in 30 minutes increments or anything that's appropriate, but I think face to face contact is important and documentation of it is crucial.

The other thing is, I believe for - to choose the right modality it's important. It is absolutely crucial to tour the dialysis unit and see how it works. And I believe that sometimes education's are done at the site - at the physician's offices cannot provide this because of their room constraints, time constraints, and other issues because you just don't have a unit there, right there.

So I think allowing outside education, meaning that it's not done at the physician's office is very important as well. Thank you.

Natalie Highsmith: Thank you.

Operator: Thank you. The next question in queue is from (Paul Smedfort) from Virginia. Your line is now open.

(Paul Smedfort): Yes we just to reiterate we the importance of face to face is important and want to concur with Ms. (Jackson)'s comments on the Web, if there is Web use to buy a camera that it also be face to face.

Natalie Highsmith: Thank you.

Operator: Thank you. The next question in queue is from (Deb Williams) from Maryland. You line is now open.

(Deb Williams): Hi. This is (Deb Williams). I concur with the remarks of the previous considerations that it should be face to face in the physician's office as the law intended and that if it a group, it would be a small group as the comments, I think, made by Northwest Kidney.

All of the groups before, prior to the benefits the group were probably larger. That was a byproduct of being almost virtually a volunteer effort and a service provided for the public good, but this is actually an education benefit.

And we think that probably depending upon the patient's ability to travel and their health, you know, you could easily the six sessions becoming 30 minutes each.

We do think, however, that since the law said that dialysis facilities could not provide the service, until the law changes we - 'til the law changes, that may not be the best site of service.

Also, typically in the physician's fee schedule, within that structure, it usually has to be under the physician's supervision. And we think under the physician's supervision is a key component there.

Natalie Highsmith: Thank you.

Operator: Thank you. The next question in queue is from (Dorian Shatell) from Wisconsin. Your line is now open.

(Dorian Shatell): Hi. And again, from Medical Institute in Wisconsin. I wanted to comment that we were a subcontractor on the project to evaluate the dialysis facility compare Web site. And in the course of that project, we conducted focus groups all over the country, focus groups and triads and one on one interviews with CKD patients and their family members.

And something that really struck us, because we required as part of this contract, that we only talk to CKD patients who had received pre-dialysis education. We never wanted to be in the position of being the first people as part of a research study to tell somebody that they needed dialysis.

So we recruited patients through CKD education programs. They varied all the way from 15 minute one on one with a nurse to six hour structured courses. And something that really struck us in the course of our research, was that the patients who had received one on one education did not feel that they had been educated when they showed up in those focus groups, because we did ask them about that.

So, we really believe that it's important to have patients be in a structured group setting. I personally do not think it matters, particularly in rural areas, it's important to have the flexibility, of allowing those group sessions to possibly be done via the Web versus face, you know, versus in a room together.

But should begin with group sessions and then to end with a one on one session, so that after having had the benefit of sharing questions that other people posed, that perhaps one patient might not have thought of, of realizing that you're not alone, just by the virtue of the fact that there's a group of people there in the same boat with you and possibly that group even being able to support each other down the road after that.

Then you have a one on one session, so that patients can get their specific personal questions answered and that would be our recommendation.

Natalie Highsmith: Thank you.

Operator: Thank you. The next question in queue is from (Mary Churchill) from Nebraska. Your line is now open.

(Mary Churchill): Yeah, this is (Mary Churchill) again in Lincoln with Lincoln Nephrology. I just would like to reiterate and support that the face to face could be done through teleconferencing or the Web. We would lose a lot of people that are out state and especially elderly if we - if they had to have in person face to face visits. Thank you.

Natalie Highsmith: Thank you. Okay, (Amanda) we have time for one final comment.



Operator: Okay. Then the last question comes from (Laura Gamba) from Florida. Your line is now open.

(Laura Gamba): Thank you. We're the QIO from the Florida and the ESRD network as well. And as we've been listening to all the conversations, we just wanted to add and perhaps this is just an assumed thing that's going to happen, but we want to make sure that we mention that we're dealing with a diversity of ages with our chronic kidney disease patients, so we want to make sure that modalities that are used are going to be appropriate for whether the person is 16 years old or 65 and that's where the, you know, the telemedicine or the use of the computers or iPods or, you know, those types of things may not be appropriate for some of our older individuals.

Likewise, we want to make sure that we take into effect or take into consideration, the health literacy types of capabilities of the patient, as well as the cultural diversity and their needs in terms of the cultures and the languages that they have or that they present.

We need to make sure that when we educate them, we're educating them to where, you know, when they need to give informed consent, they truly understand what it is that we're educating them on.

And did the group want to add anything else? Okay. Thank you so much.

Natalie Highsmith: Thank you. Now we will move onto our final question for feedback. Question number six is, "What are the existing chronic kidney disease education resources that are publicly available? In addition to the resources, please provide information regarding

sponsorship or funding provided to produce the existing education program.

We're taking feedback on question number six please.

Operator: This is a reminder, to ask a question, please press star and then one on your telephone keypad.

The first question's from (Dan Garver) from Virginia. Your line is now open.

(Dan Garver): Yes, hi this is (Dan Garver). I'm a writer for the National Kidney and Neurologic Diseases Information Clearinghouse. This is sponsored by the National Institute of Diabetes and Digestive and Kidney Diseases.

Our organization sponsored by NIH develops material. We are also a clearinghouse, so the clearinghouse itself has developed a set of materials with the booklet, "Choosing a Treatment That's Right for You", and also additional booklets on each of the modalities of chemo dialysis, peritoneal dialysis, and transplantation and then some fact sheets on complications and financial issues.

We have also developed some additional fact sheets as time went on, on kidney failure what to expect, that has to do with some of the complications, but we also have fact sheets on amyloidosis, anemia, renal osteodystrophy which we're changing now to CKD mineral and bone disease.

Also, as a clearinghouse, I should mention, of course, there are materials available from (MKF). (Dorian Shatell)'s group has a great resource in kidney school. The American Kidney Fund has good

materials and the American Association of Kidney Patients also has some really good materials.

But as a government entity we would be interested in working with CMS to take the materials we have in the choosing a treatment series, the kidney failure series and tweaking them to make them more appropriate.

So that's my comment.

Natalie Highsmith: Thank you.

Operator: Thank you. The next question in queue is from (Lisa Ferris) from Alabama. Your line is now open.

(Lisa Ferris): Well, I thank you so much. I wanted to make to just make one little additional comment and you did - the previous speaker job summarizing what's available in the literature now for quick reference.

I certainly want to offer the assistance of the Council of Advanced Practitioners which is the group within NKF that represents nephrology physician's assistants as well as nurse practitioners and clinical nurse specialists it comprises the membership that we also would like to be an active role or participant in development of a program of education that can be used that will give us some continuity of information that's presented so we can certainly have some equal measurement of what these patients have been instructed in.

That's all I need to say at this point.

Natalie Highsmith: Thank you.

Operator: Thank you. The next question in queue is from (Lea Beard) from Arizona. Your line is now open.

(Jennifer Casey): Hi this (Jennifer Casey) from the Southwest Kidney Institute. I just also wanted to offer that some of Baxter's materials are some of the things I've been using for education purposes, as well as the Next Stage Corporation for their home hemodialysis machine.

And I also use the Davita products as well. And Davita has a new program called, "Empower", which offers classes for three/four, and four/five pages.

(Lea Beard): And this (Lea Beard) a dietitian at Southwest Kidney Institute. And I belong to the Northern Arizona Council of Renal Nutrition. And as a group we have developed a product called, "Take Control", and it's for- we have just a regular renal component. We have a renal, like stage three, four, five, non-dialysis with a low potassium and then for diabetes as well.

And this is meant a dietitian practitioner to give to a patient to teach them how to eat a real appropriate diet based on food groups. So there's a place where we can put how many proteins they should have in a day, how many fruits, how many vegetables.

Whether they could be low potassium or not, and then given the list of foods for that patient to take home and follow at home and help them ease some of the burden of this diet.

Thank you.

Natalie Highsmith: Thank you.

Operator: Thank you. The next question is from (Keith Lester) from Massachusetts. Your line is now open.

(Keith Lester): I think the key part in all of the questions that have been answered or all the questions that have been asked here, is developing and standardizing the education that we're providing for our patients.

Through the Fresenius Treatment Options Program we provide, of course, education to stage three, stage four patients, but we also give them the resources of all the Web sites that are out there from the American Kidney Fund, the National Kidney Foundation, the Renal Support Networks, and if they're - of course, if they're unable to access the Web, we can provide them the numbers to those institutes as well.

But to make sure that they do have the ability to take home the information associated with each of the topics that we've discussed and then to be able to steer them in the right direction if they need any additional support.

Natalie Highsmith: Thank you.

Operator: Thank you. The next question in queue is from (Leanna Tistler) from Washington. Your line is now open.

(Leanna Tistler): Yes, I always present "Living With Chronic Kidney Disease Program" from the National Kidney Center and when we started education here, the standard education here several years ago, we visited and what we

found is that all the resources that were available on the Web were not enough to us.

And so we felt that there is still a need to develop more precise, more evidence based, more updated materials. And so - and more patient centered and really help literate material that's appropriate at different levels depending on where the patients are.

And so, over the last two years, we created more than 50 pieces of educational materials. Some of them are for sure and some of them are just one piece information for patients who have - these materials are very patient centered and very easy to read on a, you know, very low level or high level, depending on where the patients are. Thank you.

Natalie Highsmith: Thank you.

Operator: Thank you. The next question in queue is from (Tracy Forston) from New York. Your line is now open.

(Tracy Forston): Yeah, I just wanted to offer that other people have mentioned it, that the NKF has many materials also available and also we would like to be able to provide input from our patient advocates in terms of the materials, reviewing the materials that are being developed, so that they can give us a prospective on what patients really need, what messages really work for them, and what their experiences were when they were learning and going through this process.

And also, I didn't hear anybody mention that there are videos to take- I think someone did - that there are actually tapes on this - on these subjects as well.

Natalie Highsmith: Thank you.

Operator: Thank you. The next question in queue is from (Molly Cayhill) from Kansas. Your line is now open.

(Molly Cayhill): Hi. This is (Molly Cayhill) from Kansas City, ANNA. I just wanted to add that ANNA has evidence based fact sheets on all the treatment modalities, also anemia management and bone. That was it.

Natalie Highsmith: Thank you.

Operator: Thank you. The next question in queue is from (Beth Witton) from Kansas. Your line is now open.

(Beth Witton): Hi. My name is (Beth Witton). I work with the National Kidney Foundation but also have dealt with the Majority Kidney Program and do CKD education. The Joint Kidney Program has offered education since 1983 and it's very standardized education.

We provide a binder of education materials from a variety of organizations, not from any corporations, but just from the non-profit organizations. So for instance, we provide information from the National Kidney Foundation, from Medical Education Institute, that includes information on home dialysis central, kidney school, the Life Options Program.

We have provided information from the American Kidney Fund. They've got some really good information that people can take to the grocery store with a list of foods that are okay for people to eat.

Just a whole variety of information. It would be - it seems like it would be really good. You've got a whole bunch of people on this call that could probably submit to that email address suggestions that you could review materials, so that you could pick and choose from the different materials that people suggest.

What would be good for a standardized curriculum. But I think it's very important as other people have said, to have the curriculum be standardized, so that it's the same in Kansas where I live as it some place else.

And also to look at the diabetes self management education program and model what you do kind of along the lines of how they do what they do, because getting outcome data is also really good.

The Missouri Kidney Program does pretests, post tests with the patients that attend our classes and we've gotten highly significant improvement in their knowledge scores and we also ask them about their modality choices pre and post to see, whether or not, they changed their minds based on what they hear during the course as well.

So our course is targeted to CKD for stage four patients. We get referrals from the physicians. We also get referrals from nurses. We get referrals from patients too. They can call us and we accept them. We also educate their families, which I think is really important, because that's their support system.

So I think it's important in whatever you do to encourage the patients to bring family members or support persons with them.



Thank you.

Natalie Highsmith: Thank you.

Now we will take feedback on all of the questions, one through six. We have reached our ten minute allotment for question number six, so now this is open feedback for all of the questions.

Operator: Thank you. As a reminder, to ask a question, please press star and then a one on your telephone keypad.

The first person in queue is (Delores Pena) from Florida. Your line is now open.

(Delores Pena): I was actually responding to the last one, but I'll take the opportunity. Someone previously had mentioned the assessment of preferred learning style and I think that that's truly important when we're considering education resources.

Many of our patients have visual impairments, don't read well. So having DVDs as a option. There are some out there, but certainly not as much of we have in terms of written literature.

And one of the things that I found is for patients who guided their preferred learning style, it allows a couple of family members to watch the DVD together and discuss it as a family.

So I would like to see more DVDs available.

Operator: Thank you. The next person in queue is (Joyce Jackson) from Washington. Your line is now open.

(Joyce Jackson): Yes, there's three things I'd like to say. One is on that last question of material availability, it would be ideal if the material could be accessible by qualified providers providing the education on an updatable basis.

We have found that as soon as we develop something and try it for a while, we recognize we need to update it and change it. And so the equivalent of a site, a Web site or something where individuals could go, but that it could be kept up to date with the changing evidence in our field, which is changing, so that would be ideal. That would be the dream instead of hard copy written things that cannot be kept current giving the changing evidence.

The second comment is, I would be - we didn't talk about the law says six sessions, but it didn't say how long. So I'd like to request that the benefit be structured to fund the time needed to cover such extensive and life changing topics. The average cost to cover a dialysis patient is about \$60,000 a year from Medicare, and so it seems like the benefit should be structured to pay for perhaps six, up to 60 minute sessions, so that this extensive material could be covered.

A 30 minute session maybe appropriate for the individual's learning style, but ultimately it'd be great to have 360 minutes of teaching time covered by the benefit.

And finally, as a dialysis unit and others have referenced Fresenius and Davita, I would request that dialysis programs be allowed to continue to provide free group classes on these issues to stage four and five patients, because we're not considered qualified providers under the law, presumably that would not be violation of the law.

Thank you.

Operator: Thank you. The next question in queue is from (Lisa Ferris). Your line is now open.

(Lisa Ferris): Thank you so much and this has been a great conversation and very educational for me. We haven't addressed documentation of the patient's education and one place that I think it makes a lot of sense to have this evidence documented so we can retrieve of this, eventually through the USRDS database, would be on the 2720A, that that area, I think item number 26 now, asked if a patient has been informed of just kidney transplant options, but to flush out that form a little bit to talk about the patient's education.

And what might be important to track, interesting to track, would be time of education to time of onset of dialysis. And you know, it might be very interesting to see if there was something that occurred as a result of education, which I think this is our objective is to delay in time of onset of dialysis

So, I'm thinking about how this information is going to be documented and then retrievable so we can use for future program improvement.

And that's it. Thank you.

Operator: Thank you. The next question in queue is from (Sally Rice) from Kentucky. Your line is now open.

(Sally Rice): Yes. Again I'm with the University of Louisville Kidney Disease Program and Immediate Past Chair of National Kidney Foundation's

Council of Nephrology Social Work. And the one point that I think I would like to reinforce is the disparate learning styles as well as the extremely disparate ability to be ready for information and to retain information.

What I've heard is such a huge range of information and even in six hours, I think we need to be very careful that we give them what they need to start and make the choice and be ready for dialysis, but I think they're still going to recognize that there is a huge amount of education and adjustments as they go along.

And so I would encourage as much education time as possible, but - and again with a multidisciplinary team, because what do you do in a class of even ten people, when someone is crying the whole time, because they are just devastated?

No one is going to learn in that class and I think things like this really need to be considered. Thank you.

Operator: Thank you. The next question in queue is from (Dorian Shatell) from Wisconsin. Your line is now open.

(Dorian Shatell): Thank you. I just wanted to make the point that - I actually wanted to go back and address question one. I couldn't get my phone to work, by hitting star one.

I wanted to say that we really believe that applications for -okay the people who deliver the education, in addition to having a specified professional background, whether they are an advanced practice nurse, a social worker, a dietitian, nephrologist, they also need to have a

minimum of a certain amount of experience caring for people with CKD and delivering CKD self management education.

And I believe that we really need to follow the diabetes education model and there should be a certification exam, but it should be a CKD Certification that is required before this education will be paid for.

In terms of the length of sessions, I'm unhappy, I guess, that I didn't realize that the length of sessions had not been specified. I actually believe that it should be two hours per session, if possible, minimally an hour.

I don't think three hours total is enough to cover the breath of information. It's really important also that we be thinking about teaching people to fish, not just giving them a fish. Handing over facts isn't going to do the trick. We need to be building patients as self managers and helping them find out how to learn more after the sessions are done.

And finally, I just wanted to echo that the idea that I heard about tracking whether people received CKD education on that 2728 form, I think that is a genius idea. Following that information, keeping it in USRDS, so that we can cover it from year to year and hopefully see that number trend up, is really going to be invaluable to the renal community.

Operator: Thank you. The next question is from (Dell Tichano). Your line is now open.

(Dell Tichano): Hi. This (Dell Tichano) from the National Kidney Foundation. I wanted to thank you for this opportunity, this Open Door Forum this

afternoon and to request that CMS consider a follow-up Open Door Forum for the - additional questions that might inform the implementation of this benefit.

Thank you.

Operator: Thank you. The next question is from (Sue Kerry) from Louisiana. Your line is now open.

(Sue Kerry): Hi. I'm (Sue Kerry). I'm President ANNA. And I'm also a nurse practitioner in Baton Rouge, Louisiana. And I just wanted to take the statement that we're appreciative of this call and all the pertinent suggestions that were submitted.

But I just wanted to also say as an organization of about 1,200 nurses, that we would more than happy to offer to CMS a lot of our resources which a lot of our member's expertise to assist especially with questions number three and four when it is - the suggestions that were put forth about what the patient's need in the educational materials and what to include.

So anyway, just wanted to let you know we appreciate it and thank you.

Operator: Thank you. The next question's is from (Lea Beard) from Arizona. Your line is now open.

(Jennifer Casey): Hi this (Jennifer Casey) at Southwest Kidney. I just wanted to agree with the comment about the education session should be two hours. That has been that my experience so far as one on one as well as group, have been two hours or more. They're very time consuming.

And in a given day, I will have- I will only see between three or four patients a day. So that should be in consideration if this is going to be billable service. The maximum amount of patients on one on one will be three or four patients a day and that's maybe a half hour break to grab lunch.

So they do go sometimes two and a half hours. Thank you.

Operator: Thank you. The next person in queue is (Dan Garver) from Virginia. Your line is now open.

(Dan Garver): Hi. (Dan Garver) again. I mentioned that I was with the National and Neurologic Diseases Information Clearinghouse. I forgot to mention that I am also a kidney patient. I've been doing peritoneal dialysis since 2005 and I just wanted to add from my own experience that a lot of the education I got from - was from my dialysis nurse as I was - but that was when I was already into treatment.

I was in an unusual situation in that I was writing for the clearinghouse knowing that I had stage three and stage four kidney disease, so my work was sort of doing my own research. Unfortunately, most patients don't have that opportunity.

But I was wondering if there will be an opportunity as this process goes forward to get some more feedback from patients themselves into what kinds of experiences they had and what was helpful to them and also whether there might be a role for patients to help others who are coming after them to let them know what they - what people in stage four have in store for them.

Operator: Thank you. The next question in queue is from (Beth Witton) from Kansas. Your line is now open.

(Beth Witton): This is (Beth Witton) again talking about Missouri Kidney Programs. The sessions for Missouri Kidney Program that have been held for the last 25 years are an hour long for each topic. There are three topics on a day with 15 minute breaks in between, so that people can talk with each other, talk with the speaker, get up and move around.

We do two afternoon classes on a weekend, on Saturday and Sunday, so that the patient's family can come or the patients who are working can come.

And so far as the number of people involved, it's a really good use of time to have as many people as you can get at a class. We had a class a couple of months ago where we had 23 patients and the family members of those patients there, so there were over 40 patients and family members.

People did not seem to be constrained to ask questions. It as very, very well received. We got very high marks on those classes. The speakers all said that it was a good class. People were very open. They also were able to hear comments from other folks, so they didn't have to try to think up a questions. They probably got questions answered that they hadn't even thought of to ask.

So I'm not sure that it's important to limit the class size to three or small numbers. I don't think there should necessarily be a limit. That's it.



Operator: Thank you. The next question in queue is from (Tracy Forston) from New York. Your line is now open.

(Tracy Forston): Hi, I just wanted to reiterate the gentleman's comments in terms of having a patient perspective in the development of these materials. I can't stress the importance of that and we hear from our patients all the time and so (Leslie) who was on our call a little earlier, she's actually the chair of the NKS Patient and Family Council.

So we have several patients from around the country that would be willing to provide input and their perspective, which I think, again would be critically important for other patients to learn from other patients.

Operator: Thank you. The next question in queue is (Sheila Winer) from New York. Your line is now open.

(Sheila Winer): Hi. Thank you again. I'd like to the discussion also that we have found family members are a critical component of the education. I think we all know when we go to the doctor and learn about an upcoming surgery or anything related to our medical care, it's always helpful to have a family member listening in as well.

We know in our experiences when we've conducted these group educational programs around the country, that often 50% of the participants are family members. So we would hope that the education that's provided through this benefit for people with CKDC for us encourages family member participation.

Operator: Thank you. The next question in queue is (Jill Bertan) from Massachusetts. Your line is now open.

(Jill Bertan): Thank you. I just wanted to reiterate the importance of self management of teaching patients self management and because of that, I think it would be best if we could have some follow-up sessions with patients and not just consecutive training, because a lot of times people will try a new behavior and then need follow-up support or be more ready for it a month or two months later and so I would not vote for only consecutive sessions.

Operator: Thank you. The next question in queue is from (Deb Williams) from Maryland. Your line is now open.

(Deb Williams): All right. Thank you. We'd like to recommend that CMS and, as you know, Baxter has a long experience. We're very proud. We've educated over 8,000 patients.

However, we were a long supporter of this proposed benefit, because we realized that large groups and the way that people were doing before was a Medicare benefit, was not the best and most ideal way to go about it.

Is to recognize the real need for more clinical involvement in the patient's lives because so much is at stake. So again, we'd like to reiterate that this is a clinical benefit. I think it's very interesting. We've been thinking about it as 30 minutes. I've been very interested to hear people thinking that you know, it could take you know, much more significant time and I think that's, you know, it's kind of important.

But again, is our comment we hope that CMS realizes that this is a clinical benefit on a physician's fee schedule, and therefore, the perfect

model based upon what might have been happening now so that doesn't exist, and we commend you for your effort in trying to create a better model.

Operator: Thank you. The next question is from (Beth Witton) from Kansas. Your line is now open.

(Beth Witton): I forgot to mention before, that one of the things Missouri Kidney Program does for its treatments options classes is to have a nurse present the information, whether it's a nurse that is a home training nurse for the hemo-dialysis classes or a PD nurse for the PD class and transplant coordinator for the transplant class.

We also have patients that have been on their treatment option for at least a year who share their experiences with the patients that are there. So that, you know, they can explain to the patients where they were when they were sitting in those chairs, the things that they looked at when they were trying to choose a treatment, things that they did to help themselves so far as self management.

So if there could be a component of the mentoring of having a patient share their experience that would be good too, as well as a living donor - the living donor transplant.

Operator: There are no more questions in queue at this time. But as a reminder, if you wish to ask a question, please press star and the number one on your telephone keypad. Okay. Final remarks.

Natalie Highsmith: Yes, we wanted to thank all of you for providing your feedback. If you do have questions or additional information you would like to provide us on the topics discussed today, please email this information

to us at [ckdeducation@cms.hhs.gov](mailto:ckdeducation@cms.hhs.gov). Again, that's  
[ckdeducation@cms.hhs.gov](mailto:ckdeducation@cms.hhs.gov).

Thank you and have a great afternoon.

Thank you (Amanda). Can you tell you how many people joined us on  
the phones?

Operator: One twenty six.

Natalie Highsmith: One twenty six. Thank you.

Operator: This concludes today's conference call. You may now disconnect.

END