National Institutes of Health National Institute of Diabetes and Digestive and Kidney Diseases A Scientific Workshop on Post-Dialysis Fatigue

Virtual Meeting May 22–23, 2023 EXECUTIVE SUMMARY

Background and Overview

On May 22 and 23, 2023, the National Institutes of Health (NIH) sponsored a Scientific Workshop on Post-Dialysis Fatigue (PDF) hosted by the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK). More than half of people on long-term dialysis suffer with debilitating fatigue from their treatment. Post-dialysis fatigue (PDF) is underrecognized by clinicians, and the scientific literature on PDF is disproportionately sparse relative to the large burden it imposes on patients. There is a lack of objective measures to identify and measure PDF such as diagnostic criteria and outcome assessments including validated patient-reported outcome measures, and biomarkers.

NIDDK convened a virtual meeting of people with kidney disease, clinicians, researchers, and members of the end-stage kidney disease community, seeking their collective expertise and engagement to identify scientific gaps in the field and opportunities to move the field forward for an overlooked complication of dialysis treatment. More than 175 participants attended the workshop.

An External Organizing Committee composed of clinicians, researchers, and a patient representative was recruited to work with an Internal Organizing Committee comprised of NIDDK leadership and staff members to prepare the meeting agenda.

The objectives of the workshop were to:

- Define the current state of the field.
- Learn from the experiences, consequences, and aspirations of people with PDF.
- Leverage knowledge from other scientific fields of complex clinical syndromes to best research approaches for PDF.
- Identify immediate areas of scientific inquiry: establish a universal case definition, diagnostic instrument, descriptive epidemiology, and initial mechanistic biology. Such work forms the scientific platform for future development of therapeutics, rehabilitation, and dialytic care paradigms to mitigate the symptomatology of PDF.

The workshop opened with remarks from the Director and a Program Officer from the NIDDK Division of Kidney, Urologic, and Hematologic Diseases, followed by two patient lectures, four scientific lectures, and two breakout sessions that examined PDF from multiple perspectives. During the lectures, patients and their caregivers described the burden and impact of PDF, clinicians outlined the current PDF therapies, which are minimal and inadequate, and researchers described possible cutting-edge methods that could be used to assess PDF and considered lessons learned from similar

conditions. During the breakout sessions, patients, caregivers, researchers, and clinicians prioritized steps to advance the understanding of PDF and its underlying biology for a robust scientific platform for subsequent work on therapeutics or practices.

Session 1: A Call to Action

The workshop opened with a moderated panel discussion among patients with PDF and their caregivers. The conversation provided an overview of the dialysis experience and the burden imposed by kidney disease and PDF.

Key concepts

- PDF is more profound than being tired, as it can involve the complete loss of mental and physical function. This includes medical complications and disability with a fall in one's social standing. Impairments in functional status can limit life participation leading to loss of employment, independence, purpose, and friendships. Divorce and financial hardship were also common.
- The term "fatigue" has different meanings in medicine and common usage that can extend beyond just being tired. This term minimizes the experiences of patients with PDF and contributes to the stigma surrounding the condition. This is supported by studies in myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), which describe the stigmatizing effect of this diagnosis and dismissiveness by the healthcare community, in part because the term fatigue was the label associated with their disease. A National Academy of Medicine report recommended a new ICD10 code for ME/CFS that makes no reference to the word fatigue or neurasthenia.
- The onset of symptoms (fatigue) occurs during or right after the treatment. The fatigue is typically not severe enough to mention to the dialysis staff or manifest as physical/cognitive impairment as the person is leaving the unit, however, the fatigue escalates to its maximus after treatment when the patient is at home. As such, dialysis staff and health care providers may not grasp patients' experiences related to PDF and miss how this is impacting their life.
- Ultimately, the panel questioned the appropriateness of the "post-dialysis fatigue" label and challenged the community to derive a new diagnostic term with semantics that reflect what people with PDF experience.

Session 2: The State of the Science and Practice

Speakers discussed the current state of the science and medicine of PDF. Presentation topics included epidemiological aspects of the condition; clinical presentations, and prognoses; impact of in-home dialysis on PDF; and current practices. There was general agreement that PDF is distinct from the day-to-day fatigue experienced by many patients with end-stage kidney disease. The average patient–physician encounter in a dialysis facility lasts between 15 seconds and 2 minutes, which likely discourages discussions about non-urgent and non-medical aspects of the illness experience and how treatment is impacting patients' lives outside of the dialysis facility.

Most patients take several hours to recover from a hemodialysis session. While fatigue is a key aspect of the post-dialysis experience for many patients, other symptoms (e.g., cramps, headaches, nausea, vomiting, dizziness) may concurrently raise the possibility PDF is a syndrome with clinically meaningful subtypes. Treatment directed at a single etiology might not lead to population-wide improvements in clinical trials. To advance care, interventions may have to address multiple components and variants of the disease through multi-modal and/or personalized therapy.

Key Concepts

- Epidemiological evidence identifying potential contributors to PDF (e.g., dialysate sodium, ultrafiltration rate, intradialytic hypotension, myocardial stunning) is inconsistent. No clinical trials have been performed to establish causality or determine whether modifying these variables impact PDF. These studies use "recovery time" as a surrogate measure for PDF when "recovery time" has not been validated to be a robust outcome for PDF. Clinical trials to test the safety and efficacy of potential interventions (e.g., dialysate sodium, intradialytic exercise, depression management, anemia management, psychosocial support, dietary interventions, anti-inflammatory therapy, novel targets) will eventually be needed.
- Clinical trials have shown no efficacy for changing the blood flow rate or hemodiafiltration in improving dialysis recovery time. Post-hoc analyses of other clinical trials have suggested benefit with short daily hemodialysis.
- Alternatives modalities to hemodialysis (e.g., peritoneal dialysis, frequent home dialysis) should also be evaluated and considered.

Session 3: Lessons Learned

Presenters discussed clinical and patient perspectives on fatigue and lessons learned from myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), and Gulf War Illness. The following concepts below were identified.

Key Concepts

- Fatigue is a multidimensional condition with no consensus definition, no single cause, and no diagnostic test. Fatigue is measured across several domains (e.g., physical impairment, mental impairment, quality of life, disability) using self-reporting measures (e.g., diaries, logs, questionnaires) and complemented by objective measures (e.g., maximal oxygen consumption, neuropsychological tests, physical capacity testing, changes to employment and income).
- Factors associated with poor ME/CFS prognosis (e.g., older age, less education, longer duration of illness, greater fatigue, psychological disorders) might also play a role in PDF.
- For diseases defined purely by symptoms, simple case definitions tend to be highly sensitive but less specific. To manage disease misclassification, case specificity should be prioritized over case sensitivity. A case definition with high specificity increases the accuracy of effect estimates for risk factors and potential interventions.
- A PDF study starts with clinicians and patients working together to formulate a case definition and causal hypotheses. Data from patient interviews before, during, and after hemodialysis could be used to uncover subtypes. Use of statistical tools such as principal component analysis (PCA) can quantify the statistically core components of the case definition. Case-control or cohort studies are designed to test environmental and biological risk factors. Study findings should be validated in a larger and more generalized population.
- Because the etiology of Gulf War Illness is confounded, a systems biology (i.e., multi-omics) approach—incorporating differential gene expression, biological pathway analysis, and knowledge networks—was necessary to evaluate associations between changes in Gulf War Illness severity and gene expression levels. Multi-omics approaches revealed that inflammatory pathways are differentially perturbed in patients with Gulf War Illness. A similar approach may be used to study PDF.

Breakout Session 1

Workshop participants described their responses to the first day's session and discussed topics relevant to the main theme of the workshop. Guiding questions were provided to frame the discussions. Examples of feedback, roadblocks, gaps, and strategies shared in response to the guiding questions are summarized below.

What surprised you the most about the presentations we heard today?

- Patients expressed surprise (1) regarding how long it took to convene a workshop about PDF, (2) the lack of a uniform definition for PDF, and (3) the scarcity of relevant research.
- Individual patients were surprised to learn that they were not alone in experiencing the complexity of fatigue and how it impacted their livelihood through divorce, loss of employment, and financial downturn. At the same time, it was also noted that patients who were relatively privileged from a socioeconomic perspective still experienced the ill effects of PDF.
- Patients spoke of the gap between what care the clinicians provided and commented that it did not align with the needs of the patients. PDF served as an example of a "blind spot" in that PDF is not visible to the clinicians who care for them. Clinicians tend not to ask patients about their needs and patients tend not to tell, as they do not expect much can be done to mitigate PDF and they believe it is something patients must accept. A deeper documentation of the patients' PDF experiences is needed to improve patient-provider communication and collaboration in the management of PDF.
- Despite the paucity of literature, it was surprising to learn that there are some low profile studies on PDF that employed basic capabilities to measure generalized fatigue and risk factors associated with PDF; however, these findings are from small centers, had methodological flaws, and lacked reproducibility needed for widespread use in clinical practice.

What has been your experience with PDF?

- Patients reported feeling exhausted, dizzy, and light-headed, as well as experiencing blurry vision, itchiness, cramps, and sensitivity to light and sound after treatment. PDF symptoms result in severe physical, mental, and emotional burdens.
- Patients pointed out the lack of individualization of care during dialysis. For example, some dialysis facilities do not allow patients to eat light snacks or to cover their faces to sleep during treatment, factors that might shape their experiences of dialysis and what follows each treatment.
- Patients described a tendency to minimize or conceal their symptoms because they wanted to appear functional. Patients also perceived little could be done for PDF and that providers did not want to hear about their fatigue experiences.
- Many patients drew a link between what happened during the dialysis session (such as intradialytic hypotension) and how it worsened their symptoms during and after the treatment. The rapid removal of large volume (or "crashes") was cited as trigger for PDF. Some patients developed anticipatory anxiety for such impending "crashes," which worsened the patient experience.
- Patients agreed that PDF was less severe when they changed from hemodialysis to more frequent, lower blood flow rate dialysis performed at-home.

What research questions about PDF should be tackled first?

- A universal case definition of PDF and the characterization of its symptoms, and a subtypes definition, if applicable.
- A robust conceptual model of PDF informed by qualitative studies, clinical risk factors, and biological markers. This will provide a common framework to guide future hypothesis generation regarding etiological factors underlying PDF.
- PDF research should consider patient priorities and incorporate mental health components.
- Research could be more inclusive with the lived experiences of children undergoing hemodialysis.
- The economic effects of PDF should be quantified from the perspective of the patient and of society.

What kinds of studies do you think are needed to answer these questions?

- Qualitative studies (e.g., interviews, ethnography) of the patient experience and how this relates to the dialysis procedure is foundational work towards developing a patient reported diagnosis or outcome.
- Studies should incorporate large data sets with sufficient power to identify subtypes and unsupervised clustering techniques (e.g., PCA).
- Different dialysis modalities should be compared, and patients who do not experience PDF should be used as comparators.
- Prioritize interventions that provide significant improvements to symptoms and outcomes that matter to patients.
- Define the natural history of PDF: temporal (within treatment) and longitudinal (over many months) trends (e.g., improvement or worsening with time).
- Implementation science should be leveraged so future interventions can be introduced into practice.

Session 4: A Word from Patients

The patient speaker highlighted an American Association of Kidney Patients survey revealing approximately half of people undergoing dialysis experience a decline in their stamina and energy levels. Moreover, the capacity of people with PDF to perform either full-time or part-time work is diminished. The speaker expressed a message of hope based on 10 years of research and advocacy, which resulted in significant scientific achievements such as the passage of the HIV Organ Policy Equity Act in 2013; development of the Living Donor Protection Act of 2023; and engagement of kidney patients by the U.S. Congress, U.S. Department of Labor, U.S. Department of Health and Human Services, U.S. Food and Drug Administration (FDA), White House, and World Health Organization.

Key Concepts

- Patients are not well informed about the implications of their care choices, including income loss and long-term financial effects. Dialysis saves lives but not necessarily livelihoods.
- Dialysis patients often depend on disability income at some point in their illness trajectory, which may be at odds with the patient's own occupation given their education, training, and work experience.
- The patient perspective must be central to research and advocacy efforts.

Session 5: The Science of Quantifying Fatigue

Presenters outlined qualitative and quantitative tools/methods for measuring clinical fatigue. Clinical outcome assessments (COAs) must be developed for PDF and should reliably quantify the concept of interest (i.e., specific aspects of a patient's experience or clinical/biological/physical/functional state that the assessments are intended to capture). Concepts of interest, when measured properly, reflect an aspect of health that is important to patients and is modifiable by potential interventions that result in clinically meaningful within-patient changes. COAs encompass patient-reported outcome (PRO) measures, observer-reported outcome measures, clinician-reported outcome measures, and performance outcome measures.

Patient participants desired to be partners—not test subjects—in research related to assessing PDF. Data collected from these studies should be shared with patients in the public domain.

Key Concepts

- Collect qualitative data to uncover the patient experience following dialysis treatment to inform theoretical models. These models guide initial hypothesis generation and testing, towards the development of potential interventions for PDF. Qualitative methods can support the immediate need to develop a PRO for PDF.
- The Delphi method is a structured panel communication method to establish a consensus on complex, controversial, or novel qualitative problems. This method solicits opinion through questionnaire responses and relies on systematic feedback and iteration to arrive at a group consensus. This method could be used to agree on case definitions and/or measurement priorities for PDF.
- Developing a PRO should include multiple stages: (1) concept elicitation to select appropriate item content (e.g., interview, focus groups); (2) cognitive debriefing to determine content validity (e.g., think aloud interviews); (3) psychometric validation to determine construct validity and reliability (e.g., cross-sectional surveys) and responsiveness/sensitivity to change (e.g., pre-/post-intervention surveys); and (4) translation and cross-cultural adaptation.
- The Food and Drug Administration provided a regulatory framework for drug development centered around <u>clinical outcome assessments</u> (COA). The concept of interest (PRO) is framed within its <u>context of use</u> which defines where, when, with whom, and how the PRO will be used. The PRO must be <u>fit-for-purpose</u> in that the PRO is sufficiently valid within its context of use.
- Self-reporting tasks are associated with multiple challenges, including memory limitations, cognitive heuristics, and summary processes used by the human brain. To avoid these biases, recall periods should be limited, precise questions should be asked, and queries should be limited to information that can be recalled.

- Ecological momentary assessments (EMAs), which involve collecting data in real-world environments as individuals go about their lives, attempt to avoid the error and bias associated with retrospective assessments. EMA hold the potential for the mass collection of data for secondary analysis to define the dynamic associations between variables, increased data granularity, and effect modification testing by context of use.
- Anchor-based methods define meaningful within-patient score changes. Anchor-based approaches use an external indicator, called an "anchor," and differences can be determined either cross-sectionally (anchor differences between clinically defined groups at one time point) or longitudinally (change in the anchor scores of a single group over time).

Session 6: Social Factors, Discovery, and Adoption

Speakers discussed PDF from a social justice perspective. Social determinants of health (SDOH) are environmental conditions that influence a wide range of health, quality-of-life outcomes, and risks. SDOH might affect PDF at the individual biological level (e.g., physiological stress responses, inflammation, epigenetic changes, microbiome); individual behavioral level (e.g., time to sleep/rest, coping strategies, access to transportation, quality of housing, food security); interpersonal level (e.g., family and friend support, provider support, discrimination based on race/ethnicity/socioeconomic status); institutional level (e.g., workplace demands and flexibility, clinical quality of care and treatment bias, quality of dialysis facilities); community level (e.g., distance from trained providers, transportation infrastructure, access to health food, neighborhood segregation and safety); and societal level (e.g., Medicare policy, laws governing workplace policies, funding of safety net clinics, structural racism).

Systems biology is used to uncover the biological mechanism of PDF. It relies on the application of computational methods to multidimensional epidemiological and biological data derived from patient questionnaires and blood/tissue samples. The process identifies upregulated genes in PDF and control cohorts to computationally determine how gene expression clusters into higher order perturbations in signaling pathways. Network analyses identify how multiple signaling pathways operate together towards the clinical manifestations of PDF.

Representatives from the Centers for Medicare & Medicaid Services (CMS) shared a roadmap to make national coverage decisions for new devices or therapies that may apply to PDF. Items and services can be covered on a case-by-case basis in the absence of formal coverage policies. These case-by-case coverage determinations are made locally by Medicare Administrative Contractors (the organizations contracted by CMS to process Medicare claims). However, CMS may undertake a national coverage determination (NCD) analysis to determine whether an item or service is reasonable and necessary for its beneficiary population. CMS has posted instructions for requesting an NCD on its website.

Key Concepts

• Patients participating in the workshop expressed that PDF is a biological phenomenon closely linked to the dialysis treatment rather than one driven by their environment outside of the dialysis unit. They were concerned that a focus on defining a biologic link between SDOH and PDF would detract from efforts to address the biological root causes of PDF. Patients also expressed concern for the unanticipated consequences of SDOH findings that could unintendedly marginalize under-represented groups, much like how the inclusion of race in the eGFR equation impacted the Black community and biased the practice of medicine. Although strong efforts should be made to understand the significance of what happens during the dialysis treatment in shaping patients' post dialysis experiences, there may be a role for health equity in the future so PDF therapies can be disseminated into practice. These factors might not be visible as they reflect

structural factors that create high performing dialysis units (e.g., low staffing at dialysis units in poor inner-city neighborhoods may limit the ability of staff to individualize treatments to minimize PDF for individual patients).

- Community resources and programs may modify how patients experience PDF; however, the community prevalence of end stage kidney disease (ESKD) is quite low such that population level interventions may not be justified.
- The CMS evaluation process is not identical to that of the FDA. With regard to NCDs, CMS is influenced by outcomes that are important to the patient (e.g., mobility, reduction number, length of hospital admission). According to CMS, quality measures address high-priority areas of need, prioritize outcomes in a patient-centered way, include a definitive end goal that the measure will improve, are specific to intended use, utilize readily available data, involve interventions that can improve performance, and allow performance comparisons among groups.
- Patients would welcome the opportunity to become involved in community-engaged research, including the opportunity to help define research questions that are prioritized by the patient community.

Breakout Session 2

Workshop participants discussed several aspects of PDF. Guiding questions were provided to frame the discussions, and group findings were presented to the full audience by each breakout session moderator.

Mechanistic Discovery

- Existing biological models for mechanisms of fatigue that might apply to PDF include ME/CFS, Gulf War Illness, post-chemotherapy fatigue, and long COVID. Animal models for PDF are limited and should be developed.
- Commonality across fatigue experiences was noted, and fatigue was hypothesized to be a central output from multiple upstream pathways. Multiple sources and forms of fatigue exist (e.g., comorbid conditions, medications, treatment factors, symptom clusters), and these might vary in their causes and underlying mechanisms.
- Promising approaches for mechanistic discovery include the evaluation of multiple longitudinal markers (e.g., in blood, stool, saliva), prospective assessment across co-occurring symptoms, serological testing, brain imaging, physical and cognitive performance assessments, metabolic analysis, high-resolution ecological momentary assessment to identify subtle changes in physiology, muscle characterization, and assessment of cardiac and lung function.
- Subtyping attempts to identify subgroups of PDF where the biology is different such that it impacts treatment choices and prognosis. Patients with PDF can help subtyping efforts by understanding fatigue is a multi-dimensional experience and providing their deeper experience of PDF in qualitative interviews.
- Precision medicine approaches that consider genetics, environment, and lifestyle are recommended to obtain the data that will ultimately permit clinicians to personalize individual patient experiences to optimize management approaches.

Case Definition

- A case definition is necessary for consistency across studies/practice, to meet regulatory requirements, and to appeal to funders. To find associations between symptoms and comorbid conditions and treatment strategies, the most robust symptoms must be identified.
- Patients should be consulted when formulating a case definition of PDF because the diagnosis is qualitative and based on how patients feel. The goal is to improve their wellness and experience with dialysis.
- Some people with PDF are not comfortable with the label of "fatigue," because it does not adequately convey their experience. The community could consider an alternate name for this disease that decreases stigma and legitimizes how patients feel.
- PDF measurement options include adapting and validating an existing dialysis-specific scale (e.g., <u>PDF self-assessment scale</u>, <u>Standardized Outcomes in Nephrology-Hemodialysis Fatigue</u>), and a general fatigue scale (e.g., <u>Functional Assessment of Chronic Illness Therapy–Fatigue</u>, <u>PROMIS</u> Fatigue), or ecological momentary assessment methodologies, or developing and validating a new instrument.
- The existing outcome of post-dialysis recovery time may inadequately capture the complete case definition for PDF. Resilience is an important aspect that might affect the individual recovery from treatment.
- Since it is not known whether existing PDF measurement instruments measure PDF with sufficient specificity, research efforts should use detailed clinical interviews by astute physicians and psychologists of dialysis patients during and after PDF episodes to capture the most typical manifestations. These could be incorporated into a self-rating questionnaire to be administered to enough PDF patients for principal components analysis to identify possible subtypes as part of a case definition.

Factors Inside and Outside the Dialysis Unit

- PDF is viewed by patients as a direct side effect of the dialysis treatment that can be explained by a pathophysiologic process. Thus, research efforts should focus on understanding the maladaptive biology of PDF and dialysis, and how to intervene on the pathophysiology.
- Dialysis treatment is delivered in a standardized and formulaic way; dialysis could be better if the patients were more engaged in treatment decisions towards personalized treatments, depending on the effects and outcomes observed in individual patients.
- Comments from patients implied that volume removal was a critical aspect of the dialysis treatment that had a strong bearing on how they felt during and after treatments. One patient noted that state-of-the-art approaches to dynamic fluid management and other technologies (e.g., the use of Crit-Line[®] intravenous monitors) may improve symptoms but felt frustrated that their opinions were limited and strategies that could be very helpful for guiding volume removal were not being adopted by dialysis units.
- Current practices associated with dialysis treatment are not necessarily based on strong evidence. Patients are subject to these practices without explanation and without an explicit understanding of what these treatments entail and without much opportunity to shape their own treatment.
- Patients may not experience some of the symptoms of PDF until they have left the dialysis unit (or their symptoms may become more pronounced only after leaving the facility) in which case staff are unaware that they are experiencing these symptoms unless they bring this up at a later

time. Patients sometimes assume that not much could be done to improve their post-dialysis experiences and thus, do not see the point of saying anything to their providers. Some suggested that interactions between staff and patients around the dialysis procedure could be more dynamic and give patients options to be engaged. Patients described feeling disempowered and invisibility in the dialysis unit, which could lead to a state of learned helplessness.

• "Dry weight" (i.e., body weight without excess fluid) as a goal during dialysis treatment is an estimated target, and patients suffer when dry weight is calculated incorrectly. More education for care providers is needed regarding the physiology of dialysis. Waiting till their next appointment with the nephrologist to change a dry weight is seen as problematic given the dynamic nature of volume removal during dialysis treatments.

Summary and Conclusion

PDF is a debilitating syndrome affecting approximately half of patients on long-term hemodialysis. Little is known about the causes and mechanisms of this condition, which has been underappreciated for decades. The word "fatigue" does not do justice to and potentially minimizes what patients experience after they receive dialysis, which can include both mental and physical incapacity sometimes associated with other bothersome symptoms such as nausea. PDF may comprise of several sub-syndromes with both distinct and overlapping symptoms and distinct causes.

The workshop provides a consensus on how to advance the science and clinical care of PDF through a duality of voices from both patients and the ESKD community. There is a call to action for science to identify and address the immediate knowledge gaps which include a case definition and understanding the pathophysiology. During the workshop, speakers discuss the current state of PDF science and medicine, lessons learned from similar conditions, methodologies for measuring fatigue, and mechanistic discovery. Patient participants and caregivers share their PDF experiences and express gratitude for the opportunity to participate in the workshop.

Immediate efforts will focus on a patient-centered model for case definitions, outcome measures, and mechanistic analyses of people with PDF. Future clinical trials need to establish efficacy of interventions and evaluate changes that are made to the dialysis process result in meaningful improvements for patients experiencing PDF. Patients emphasize the need to move rapidly towards developing interventions because the burden of PDF significantly impairs their livelihood.

Organizing Committees

Internal Organizing Committee and NIDDK Leadership

- Kevin Chan, M.D., NIDDK, NIH (Lead Organizer)
- Kevin Abbott, M.D., M.P.H., NIDDK, NIH
- Daniel Gossett, Ph.D., NIDDK, NIH
- Susan Mendley, M.D., NIDDK, NIH
- Christopher Mullins, Ph.D., NIDDK, NIH
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- Neha Shah, M.S.P.H., NIDDK, NIH
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External Organizing Committee

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- Mark Unruh, M.D., The University of New Mexico

Moderators and Speakers

- Sonya Brady, Ph.D., LP, University of Minnesota
- Dedra Buchwald, M.D., Washington State University
- Kevin Chan, M.D., NIDDK, NIH

- Stephanie Clark, M.D., M.P.H., M.S.H.P., CMS
- Paul Conway, American Association of Kidney Patients, Patient Speaker
- Dawn Edwards, New York State Chronic Kidney Disease Champions, Patient Speaker
- Andrew Fenves, M.D., Harvard Medical School
- Derek Forfang, Patient Speaker
- Robert Haley, M.D., Dallas VA Medical Center and The University of Texas Southwestern Medical Center
- Rasheeda Hall, M.D., M.B.A., M.H.S., Duke University School of Medicine and Durham VA Medical Center
- Julie Ingelfinger, M.D., Mass General for Children at MGB; Harvard Medical School, Caregiver Speaker
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