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Patient Panel: Adjusting to the ESRD Renal Diet

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Patient Advisory Committee (PAC) Patient/SME Panelists

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*Panelist
Introductions*

Kenneth Teasley

- PAC Advisor Subject Matter Expert (SME) with the ESRD Network of New York
- Patient Subject Matter Expert with the National Coordinating Center (NCC)
- Patient with Kidney disease for 23 years, and co-morbidities: Gout, High Blood Pressure
- Transplant patient (2016)
- Army veteran
- Originally from North Carolina

Albert Diaz-Cruz

- PAC Subject Matter Expert (SME) for the ESRD Network
- Subject Matter Expert for the National Coordinating Center (NCC)
- Caregiver for Ken Teasley
- Retired New York City school teacher
- Ordained priest
- Originally from Puerto Rico

Sherillee Rivero

- PAC Advisor Subject Matter Expert (SME) for the ESRD Network
- Subject Matter Expert for the National Coordinating Center (NCC)
- Patient with ESRD (10 years) and Lupus diagnosis
- Current treatment modality: In Center HD
- Originally from Belize

Dawn Edwards

- PAC Advisor Subject Matter Expert (SME) with the ESRD Network of New York
- Patient Subject Matter Expert with the National Coordinating Center (NCC PAC Advisor with
- Kidney Disease patient for over 25 years
- Current treatment modality: Home HD
- One of the founding members of the CKD Champions
- Native New Yorker

Audience Activity



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Which Is Right For Me?

Product A		Club Soda
Nutrition Facts		
Serving Size	12 fl. oz.	% Daily Value
Calories	0	
Total Fat	0 g	0%
Sodium	95 mg	4%
Total Carbohydrates	0 g	0%
Protein	0 g	
Ingredients: Carbonated water, sodium bicarbonate, sodium chloride, potassium sulfate		

Product B		Original Sparkling Water
Nutrition Facts		
Serving Size	12 fl. oz.	% Daily Value
Calories	0	
Total Fat	0 g	0%
Sodium	0 mg	0%
Total Carbohydrates	0 g	0%
Protein	0 g	
Ingredients: carbonated water		

Product C		Tonic Water
Nutrition Facts		
Serving Size	12 fl. oz.	% Daily Value
Calories	130	
Total Fat	0 g	0%
Sodium	55 mg	2%
Total Carbohydrates	33 g	11%
Sugar	32 g	
Protein	0 g	
Ingredients: carbonated water, high fructose corn syrup, citric acid, sodium benzoate (preservative), quinine, natural flavors		

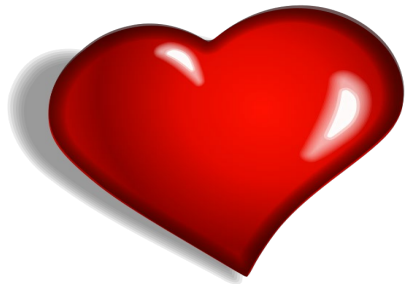
Product D		Diet Tonic Water
Nutrition Facts		
Serving Size	12 fl. oz.	% Daily Value
Calories	0	
Total Fat	0 g	0%
Sodium	105 mg	4%
Total Carbohydrates	0 g	0%
Protein	0 g	
Ingredients: carbonated water, citric acid, sodium citrate, sodium benzoate (preservative), sodium saccharin, quinine, natural flavors		

Panel Discussion

Learning Objectives

- Understanding the lifestyle adaptations for new ESRD patients
 - Overcoming loss of control
 - Diet adjustments
 - Mental / Emotional impacts
 - Self-efficacy challenges
- Identify coping mechanisms
 - Social support
 - Successful Strategies for patient adherence to diet

In one word, describe your personal relationship with food?



Ken & Albert

- Ken: Can you share with us a little about how you and Albert connected through your **“food ways”**?



Shared
agricultural
upbringing

Ken & Albert

- Albert: What role has food played in your and Ken's relationship, especially during his past and present treatment processes?



Eating Healthy to
support optimal
health

Ken & Albert

- Ken: Can you share some specific examples of how Albert has made lifestyle adjustments in support of you throughout your treatment process?



Cooking,
farmers markets

- Albert: What has been your greatest tool in making lifestyle compromises and finding solutions to challenges, as a couple?



Communication

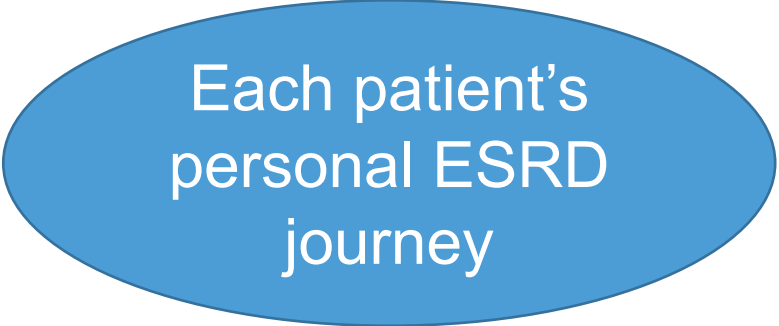
Ken & Albert

- Ken and Albert: What is the main message you want attendees to take away from your story?

Meeting patients
where they are at
in their ESRD
journey

Sherillee

- How has your current dialysis treatment changed your relationship with food?

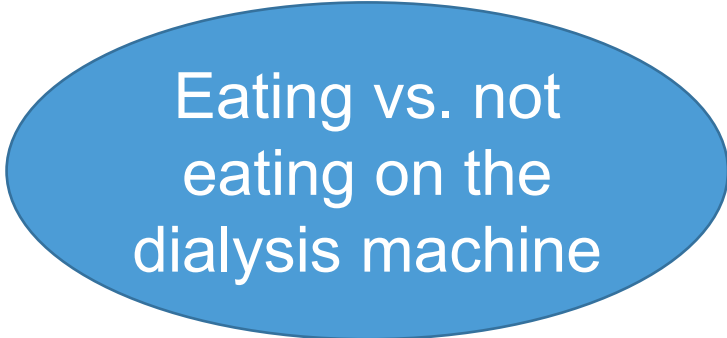


Each patient's
personal ESRD
journey

- Which foods have been the hardest to give up since you went on dialysis?

Sherillee

- Have you been able to find ways to safely include these foods in your diet?
- Are there any things you used to do when you first started dialysis that you no longer do, now that you have a better understanding on how it affects your health?



Eating vs. not
eating on the
dialysis machine

Sherillee

- What personal health goals are you working on right now, that you want to accomplish with your healthcare team's support?



Kidney
Transplant

Dawn

- Did you have any habits that you changed since your initial dialysis treatment process?
- Which food was the hardest to give up when you went on in-center dialysis?

Not eating on the machine is huge!

Dawn

- How has your current dialysis treatment changed your relationship with food?



GI discomfort,
decreased
appetite

- What are your main struggles with trying to include the foods that are healthy for you into your diet?



Living in a
“food desert”

Closing Remarks

Final Thoughts

Ken & Albert:

- Importance of caregiver support
- Shared lifestyle and values centered on food.
- Remembering to meet patients where they are at in their ESRD journey

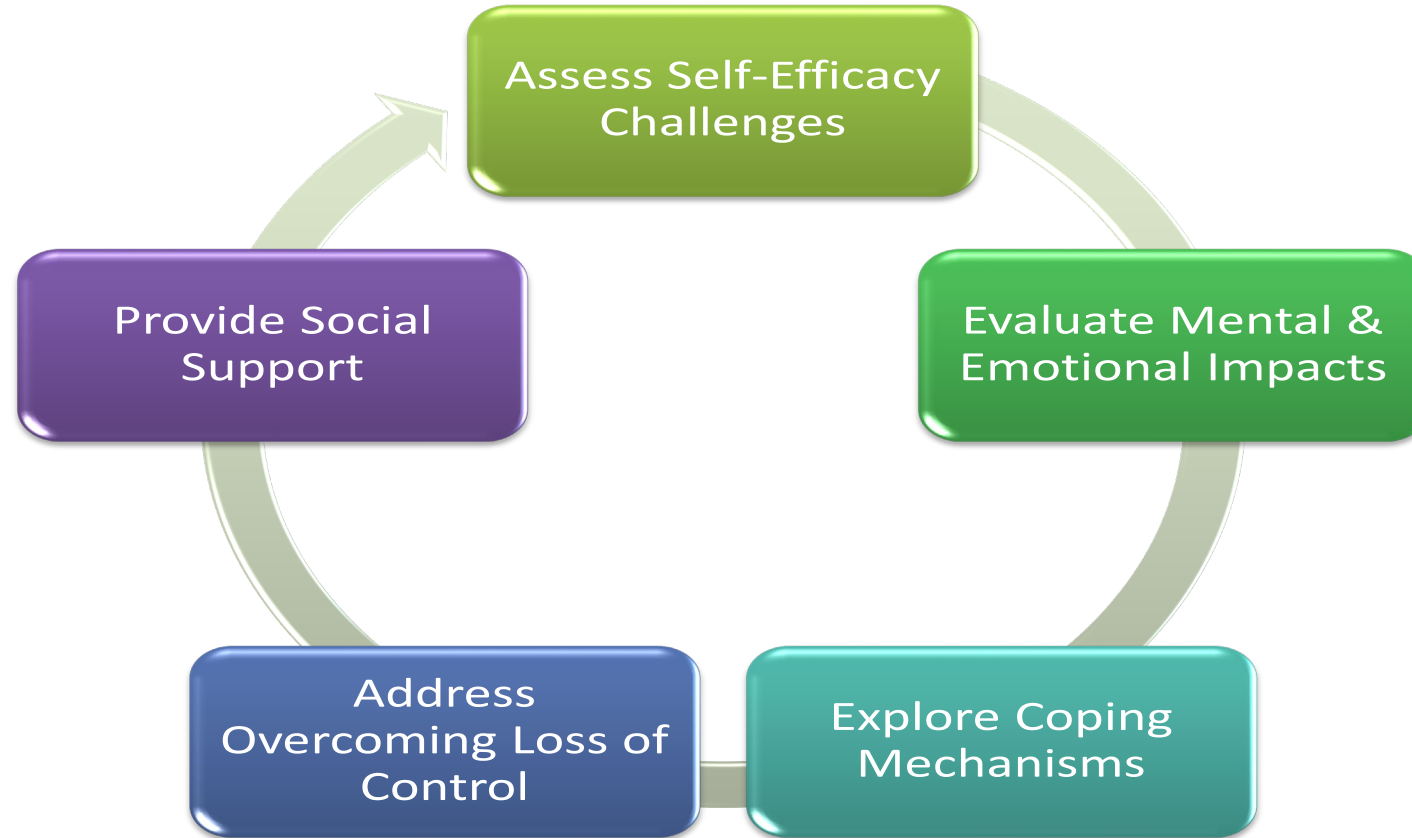
Sherillee:

- Understanding of the difficulties ESRD patients have giving up certain foods
- Helping patients achieve their goals

Dawn:

- The role identity plays with food preferences
- The socioeconomic concerns of patients living in “food deserts”

Strategies to Assist Patients with Diet and Maintenance



Questions or Comments?



Thank You!

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