Patient Panel: Adjusting to the ESRD Renal Diet

Ingris Garcia, RDN, CDN, Population Health Coordinator, IPRO
Patient Advisory Committee (PAC) Patient/SME Panelists
April 4, 2019
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
## Which Is Right For Me?

### Product A: Club Soda

<table>
<thead>
<tr>
<th>Nutrition Facts</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Serving Size</strong></td>
<td>12 fl. oz.</td>
</tr>
<tr>
<td><strong>Calories</strong></td>
<td>0</td>
</tr>
<tr>
<td><strong>Total Fat</strong></td>
<td>0 g</td>
</tr>
<tr>
<td><strong>Sodium</strong></td>
<td>95 mg</td>
</tr>
<tr>
<td><strong>Total Carbohydrates</strong></td>
<td>0 g</td>
</tr>
<tr>
<td><strong>Protein</strong></td>
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</tbody>
</table>

**Ingredients:** Carbonated water, sodium bicarbonate, sodium chloride, potassium sulfate

### Product B: Original Sparkling Water

<table>
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</tr>
<tr>
<td><strong>Calories</strong></td>
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</tr>
<tr>
<td><strong>Total Fat</strong></td>
<td>0 g</td>
</tr>
<tr>
<td><strong>Sodium</strong></td>
<td>0 mg</td>
</tr>
<tr>
<td><strong>Total Carbohydrates</strong></td>
<td>0 g</td>
</tr>
<tr>
<td><strong>Protein</strong></td>
<td>0 g</td>
</tr>
</tbody>
</table>

**Ingredients:** Carbonated water

### Product C: Tonic Water

<table>
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<tbody>
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<tr>
<td><strong>Calories</strong></td>
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<tr>
<td><strong>Total Fat</strong></td>
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<td><strong>Sodium</strong></td>
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<tr>
<td><strong>Total Carbohydrates</strong></td>
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<tr>
<td><strong>Sugar</strong></td>
<td>32 g</td>
</tr>
<tr>
<td><strong>Protein</strong></td>
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</table>

**Ingredients:** Carbonated water, high fructose corn syrup, citric acid, sodium benzoate (preservative), quinine, natural flavors

### Product D: Diet Tonic Water

<table>
<thead>
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<th>Nutrition Facts</th>
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<tbody>
<tr>
<td><strong>Serving Size</strong></td>
<td>12 fl. oz.</td>
</tr>
<tr>
<td><strong>Calories</strong></td>
<td>0</td>
</tr>
<tr>
<td><strong>Total Fat</strong></td>
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</tr>
<tr>
<td><strong>Sodium</strong></td>
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</tr>
<tr>
<td><strong>Total Carbohydrates</strong></td>
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</tr>
<tr>
<td><strong>Protein</strong></td>
<td>0 g</td>
</tr>
</tbody>
</table>

**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”?
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?

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

  - Cooking, farmers markets
  - 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?

• 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

- Assess Self-Efficacy Challenges
- Evaluate Mental & Emotional Impacts
- Provide Social Support
- Address Overcoming Loss of Control
- Explore Coping Mechanisms
Questions or Comments?
Thank You!

IPRO ESRD Network of New York
1979 Marcus Avenue, Suite 105
Lake Success, NY 11042

http://network2.esrd.ipro.org/

Corporate Headquarters
1979 Marcus Avenue
Lake Success, NY 11042-1072

http://ipro.org