

# A Call to Action: The End of the Word “Diet”

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Sticking to a diet, especially a kidney diet, is hard. People start diets and break diets. They go back on diets, and then they “cheat.” Renal diets can be complex, and many kidney patients are living with multiple health conditions that further complicate what they can, and cannot, eat. The end result is a huge challenge and a likely negative impact on quality of life. Is there anything that can be done about this?

In May 2016, The Rogosin Institute<sup>1</sup> hosted a Roundtable to bring together experts from around the country to talk about the challenges

<sup>1</sup> The Rogosin Institute is an independent, not-for-profit treatment and research center that has been providing care to patients for over five decades. Rogosin is affiliated with New York-Presbyterian Hospital, Weill Cornell Medical College and is a member of New York-Presbyterian Healthcare System, Kidney Care Partners and the Kidney Care Council. Rogosin provides patient-centered care for individuals with chronic diseases, including kidney disease, diabetes, hypertension, cholesterol or triglyceride disorders, and cancer. Having worked over the past 25 years with health promotion and basic health care in 30 countries around the world, The Institute is uniquely equipped to advance programs that prevent disease and promote good health in underserved communities.





associated with nutrition for Chronic Kidney Disease (CKD) and End-Stage Renal Disease (ESRD) patients and to develop actionable ideas to address these challenges. Roundtable participants included patient activists, healthcare providers, a chef, dietitians, policy experts, scientists, and community organizers<sup>2</sup>.

In preparation for the Roundtable, Rogosin staff members interviewed 52 ESRD patients from seven of its dialysis centers in Brooklyn, Manhattan, and Queens. Respondents ranged in age from 21 to 96, were from diverse backgrounds, and had been on dialysis for as little as two months and as long as 21 years. They discussed their experiences with kidney disease, including their food and fluid restrictions, as well as the financial burden of the renal diet. Nearly half (46%) of those surveyed said they did not feel as though they had enough money to spend on food, and 40% receive food stamp benefits. Forty-five percent said that they eat out weekly or more frequently at restaurants ranging from those providing fast food to fine dining. More than two-thirds of respondents read food labels, particularly for

sodium, potassium, sugar, and calories, but many shared that it is not always easy to interpret what they are reading. Those surveyed were clear in stating that they wished that they had more educational materials available to them (especially culturally relevant materials), cooking lessons, easier access to healthier foods, financial assistance, and, overall, more support available to them to help manage their illnesses and healthcare needs.

At the Roundtable itself, Dr. Sharon Moe, Director of Nephrology at Indiana University, delivered a keynote speech highlighting the most critical issues in nutrition as they relate to kidney disease, and Rogosin staff members presented the results of the patient interview findings (see above). Following these presentations, a lively discussion involving all participants served to further define the issues and to define actionable projects designed to improve nutrition for kidney patients.

Ultimately, the Roundtable participants agreed that there is a need for a shift in perspective regarding nutrition for patients with kidney disease. There must be a movement away from the word “diet” (generally viewed as meaning restriction) and away from telling people what they cannot eat. Instead the movement must be toward encouraging consumption of GOOD food. As emphasized at the Roundtable by Angela L. Davis, patient activist and President of For Kidney’s Sake, Inc., a patient support organization, “We must make good food – and nutrition – cool, fun, funky, and fresh.” There must, everyone agreed, be a recognition that nutrition, and good food in particular,

<sup>2</sup> Roundtable participants included: Paul Conway, American Association of Kidney Patients; Dr. Deidra Crews, Johns Hopkins University School of Medicine; Angela Davis, For Kidneys Sake; Lucas Denton, Melting Pot Foundation; Dr. Orlando Gutierrez, University of Alabama at Birmingham; Oliver Hale, chef; Richard Knight, American Association of Kidney Patients; Dr. Susie Lew, George Washington University; Jarah Meador, US Department of Veterans Affairs; Dr. Sharon Moe, Indiana University School of Medicine; Beth Shanaman, Northwest Kidney Centers; Barry Smith, The Rogosin Institute; Mandy Trolinger, Denver Nephrology; Maggie Veatch, NYC Department of Health and Mental Hygiene; Dr. Daniel Weiner, Tufts Medical Center; Dr. Donald Wesson, Baylor Scott & White Health; and David White, Independent Healthcare Advocate





is an important part of the treatment of renal disease. Put another way, good nutrition is good medicine! The participants also emphasized the **A, B, C, D's of kidney nutrition health**:

- a. Access to affordable, fresh foods
- b. Back to basics
- c. Cooking, you can do it!
- d. Deliver information a patient can understand

In order to create this shift, the consensus of the participants at the meeting was that all health professionals must work side by side with patients at multiple levels and with diverse community groups. Some specifics:

- **At the individual level**, Roundtable participants committed to exploring and endorsing the best tools to help patients manage their illness, their nutritional needs, stress, and the navigation of the healthcare system so that they receive optimal care.
- **At the community and family level**, the commitment was to increase educational efforts and access in both dialysis units and community settings. This includes organizing cooking demos, building partnerships with local community-based organizations that provide ongoing support and even more education, and promoting farmer's markets that can bring fresh, renal-friendly foods to kidney patients and their families.
- **At the academic level**, participants agreed to continue to conduct innovative research, seeking additional

funding for research specifically related to kidney health.

- **At a policy level**, participants agreed to develop a list of recommendations for better nutritional standards designed to improve nutrition, healthcare outcomes, and quality of life. Such lists of recommendations and best practices will be used to strengthen advocacy for improved food labeling, as well as enhanced insurance company and government programs (such as, Supplemental Nutrition Assistance Program – SNAP), designed to assist with nutritional therapy and encourage (and make possible) patients' abilities to improve their nutrition.

Changing our approach to nutrition will require the engagement of the entire kidney community – patients, families, friends, providers, researchers, and advocates. Immediate action and ongoing dialogue among all involved is needed. A patient-led nutrition initiative is critical if we are all going to be successful together! The Roundtable participants are anxious to hear from you as to the successes and challenges you face. They also want to hear more about what you think would help kidney patients manage their nutritional needs, and what would help improve access to good, fresh foods in your community. We want to make certain that your voices are heard! Together, we can shift attitudes around nutrition and healthy eating and improve both the quality-of-life and healthcare outcomes for the entire kidney community!