

HOW TO REACH *THE* UNDERSERVED PATIENT

BEING LEFT BEHIND IN A RAPIDLY EVOLVING MEDICAL SYSTEM

reflections from the 2018 AACR Disparities Conference

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Prologue: I have been an affiliate member of the American Association for Cancer Research for almost a decade. I have participated in their annual meetings via the Scientist ↔ Survivor Program and have used information from their *Annual Progress Report* in numerous papers and summaries written over the years. I have made long-lasting friends as a result of my involvement with the AACR and I appreciate the tremendous work that the organization has undertaken and become involved with on many fronts in the field of cancer. In 2018 I was privileged to attend the 11th AACR Conference on The Science of Cancer Health Disparities in Racial/Ethnic Minorities and the Medically Underserved. Like many others who are advocates in the cancer community I am aware that there are disparities found in virtually every aspect of the cancer experience. This conference heightened that level of awareness for me. Following these photographs of some of the people I met during the conference I will reflect on an overview of kidney cancer.



Mike Lawing & Fred Hardy

Todd Buchanan-AACR



Susie Brain & Mike Lawing



Virgie Townsend & Mike Lawing



Karen Lee & Mike Lawing

Todd Buchanan-AACR



As Dr. Chanita Hughes-Halbert of the Medical University of South Carolina Hollings Cancer Center, Charleston, South Carolina made her presentation during the opening session of the 11th AACR Disparities Conference, she displayed a slide depicting the route of Interstate 95 running across the state of South Carolina. The counties on either side of I-95 were shaded, and she commented that those counties represented a vast region where disparities of cancer care due to lack of access to treatment, a higher incidence of poverty, and several other conditions existed.

As she spoke, I reflected upon a presentation I had made in 2016 at a National Comprehensive Cancer Network (NCCN) meeting using information from a *CancerNetwork* report stating that over 70% of the counties in the United States do not have a practicing medical oncologist. Furthermore, the report revealed that although 20% of the US population lives in rural areas only 3% of medical oncologists practice there. The 2015 article added that only 2% of health social workers practice in rural areas and those who specialize in oncology are virtually nonexistent in those locations. The report found that rural cancer survivors experience greater emotional problems including distress, anxiety, and depression than their urban counterparts and that 23% had unmet needs regarding cancer information with most of them citing insufficient counseling time with their medical team and expressing a need to have additional information after their consultation. ⁽¹⁾

Dr. Hughes-Halbert's map of South Carolina with its 198-mile ribbon of concrete and asphalt zipping travelers from the populous northeast to the sun-swept beaches of Florida at 70 mph through the pine forests, farmlands, blackwater streams and swamps of the coastal plain added another strong visual image to the dilemma that so many in the medical and cancer advocacy community have struggled with for a long time; How to Reach the Underserved Patient that is being left behind in a rapidly evolving medical system?

I have pondered that question many times in my more than two decades of cancer survivorship and advocacy. I have been one of the fortunate ones that received excellent care by knowledgeable medical teams from the time of my initial diagnosis in November 1997. I have enjoyed tremendous insurance coverage and have been able to travel to receive the care that was required. My volunteer work with cancer advocacy has afforded me the opportunity to stay abreast of most of the major developments that have occurred in my type of cancer in the past two decades. I have been able to share that information with countless numbers of other patients and caregivers that I have encountered in various ways over the years.

I am a survivor of renal cell carcinoma (RCC) commonly known as kidney cancer. The American Cancer Society (ACS) estimates that more than 73,000 new cases of cancer of the kidney and renal pelvis will be diagnosed in 2019. That is just over 4% of the 1.7 million new cases of cancer that are anticipated for the year. Consequently, kidney cancer is a relatively uncommon cancer. With numbers far below those of breast, lung, prostate, and colorectal, it ranks eighth in overall occurrence. Kidney cancer ranks 6th in occurrence in men; in women 10th. While almost 15,000 people are expected to die from kidney cancer in 2019 according to the ACS there are 11 other cancers with higher death rates; twice as many people will die from prostate or liver cancer, almost 3 times as many from breast cancer, over three times as many will die from pancreatic and colon cancer, and lung cancer will have more than nine times the number of deaths (142,670 vs 14,770). Deaths due to kidney cancer are a miniscule amount of less than 2.5% of the more than 600,000 cancer deaths predicted in the US for 2019. ⁽²⁾



Kidney cancer is not only relatively uncommon, it is also not a “glamorous” cancer. It has no well-known celebrities or publicity campaigns to present its case or raise its awareness to the American public; while breast, lung, prostate, and colorectal cancers are frequently spoken of in conjunction with preventative screening for early detection and are the subject of countless press releases and reports, RCC and its lesser-known counterparts are often left out of the conversation as attention is focused on the more common cancer types. While this is understandable, given their higher incidence and death rates, the individual who is diagnosed with kidney cancer and other uncommon cancers are often faced with additional levels of disparities than those who are dealing with a more common cancer type. Almost all the “warning signs” of kidney cancer can be easily assigned to a host of other things, for example the lower flank or back pain commonly listed as a warning sign is often dismissed as a pulled muscle due to overexertion. Fatigue, weight loss, loss of appetite, and anemia can be due to a host of other ailments and conditions. A person may not even think to mention symptoms to their primary care physician during a visit; if they do, those symptoms are often attributed by Primary Care Physicians to other more commonly occurring reasons. Even blood in the urine which occasionally occurs in a person with kidney cancer is often diagnosed and treated as a bladder or urinary tract infection or kidney stones; sometimes a long period of time passes before the source is identified as a kidney tumor. Primary Care Physicians as well as urologists and many oncologists located in rural communities or smaller urban practices may seldom see a person with kidney cancer.

The urologist that removed my kidney in 1997 was located in a neighboring county of farmlands and pine forests with a population of roughly 100,000 people; I was his only patient that had kidney cancer. While his knowledge of the treatment of kidney cancer was primarily based on information he had obtained years earlier in medical school, he made a commitment to try to learn more about the disease and to give me the best possible care. When I developed metastatic disease less than three years later, he referred me to a specialist located 90 minutes from my home. This specialist was skilled in the only treatment option besides surgery that was approved for use in kidney cancer; he was one of a small number of doctors in the country that was qualified and had a trained team to administer that treatment. Much has happened in the treatment options of kidney cancer in the past two decades. Many patients with small tumors (small renal masses) are able to undergo a surgical procedure which removes the tumor and leaves the remainder of the kidney functioning and unharmed. There are other procedures such as ablative techniques that can be used to treat these tumors as well. Over 50% of the kidney cancers that are currently diagnosed are small tumors. Since December 2005 the number of agents approved for use in treating kidney cancer has grown from one to a dozen ⁽³⁾ with many more promising drugs in various stages of development and investigation in clinical trials. Virtually all the approved or trial agents are immunotherapy or targeted therapy-based treatments. Unfortunately, despite these advances, there are many surgeons who are not skilled in the laparoscopic or robotic procedures on the kidney which allow for successful removal of small renal masses; they still must remove the entire kidney to remove a tumorous mass. Ablative techniques are not available in many areas. Oncologists and urologists in smaller practices may only be slightly familiar with one or two of the dozen approved agents and offer no clinical trials. Patients who must rely on these smaller practices for their care for any number of reasons may never be aware that other treatment options are available. This situation exists not only in the rural areas of the country, it is often found in more populous areas including large metropolitan areas.

Recently I learned of a doctor with an interest in RCC who had established a practice with an urban regional hospital that had a number of smaller hospitals closely affiliated with it in a vast rural service area. In looking at the hospital's website I saw that it laid claim to providing healthcare for more than 1.2 million people in a service area that encompassed over 25 counties (please note: these numbers are deliberately underreported in this article to preserve the anonymity of this healthcare facility). I was shocked as I went to the website's information on kidney cancer to see that none of the approved drug treatments currently available for that condition were named while the two treatments listed were not appropriate for use in kidney cancer!

Efforts to reach persons diagnosed with kidney cancer who are not being treated by knowledgeable specialists in order to convey information to them about what treatments are available are tremendously challenging. Since there are no economical early detection methods available and no widespread public awareness campaigns that have been organized, a tremendous number of the thousands of new cases identified each year may never seek or learn of any options or information about the disease other than that provided by their initial encounter with a surgeon, urologist, or even a community oncologist. For various reasons many will never seek information contained in the websites of non-profits whose primary focus is on various aspects of kidney cancer; Facebook pages established by those organizations or by individual kidney cancer advocates or chat rooms devoted to that topic will never be visited. Efforts by those organizations to host and promote local support groups or patient meetings or to disseminate information through medical practices will have limited success. Both large and small medical practitioners and facilities tend to refrain from disseminating information from outside sources in a manner that reaches a substantial portion of their patients dealing with kidney cancer. Facilities that do have outside materials available frequently place them in a resource room as opposed to having them available in waiting rooms or in exam rooms. Large organizations such as the American Cancer Society or the National Cancer Institute or leading medical institutions throughout the country that have current and reliable information about kidney cancer will not be consulted by a substantial number of patients or their families including many who are dealing with complex situations and have been told by their medical teams that there is little or nothing that can be done.

Whether it is among the blackwater streams and swamps of the South Carolina lowlands, or a high-rise apartment in a huge metropolitan area, over the years there are many persons who are surviving and living with kidney cancer that is being dealt with as a chronic condition and those who have successfully undergone some form of treatment who are currently free of disease that were told at some point by a medical practitioner that there was nothing that could be done. In most instances those people sought a second opinion and embarked on a course of different treatment. Their decision to seek a second opinion was often brought about by not accepting the grim verdict that had been given and to search for additional information. Their search frequently led them to an online support group or to a Facebook page where they learned of other options. Sometimes they discovered a patient meeting or ran across information on the Internet from a nonprofit organization or a healthcare facility describing the availability of the latest treatment methods or learned valuable information from a rapidly growing number of podcast programs.

It is in the hope of locating and encouraging others dealing with this rare and complex condition called kidney cancer that this overview has been written. While there are still numerous questions and unknowns about this disease, the current array of treatment options and information available for the survivor and caregiver have increased dramatically in the past few years. As an advocate it is my continuing goal to share that information.



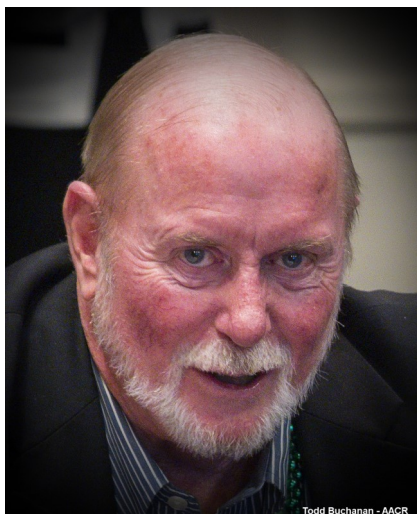
Sources: (1) Challenges of Rural Cancer Care in the United States September 15, 2015

<http://www.cancernetwork.com/oncology-journal/challenges-rural-cancer-care-united-states>

(2) <https://www.cancer.org/cancer/kidney-cancer/about/key-statistics.html>

(3) <https://www.ackc.org/approved-medical-treatments-for-kidney-cancer/>

About the Author:



Michael B Lawing lives in Western North Carolina and currently serves as Director of Outreach and Co-Chair of the Patient Advisory Board of [KCCure](#) a non-profit organization engaged in funding research in Kidney Cancer and raising patient awareness. He is a Co-Host and former Board Member of the [Powerful Patient](#) a Boston-based podcasting organization dealing with medical issues of concern to a variety of patients. Lawing has recently added his cancer and podcast expertise to a team of other cancer survivors and non-profit administrators to form [CancerCast.org](#) which focuses on cancer-related topics. Lawing has served multiple times as a consumer reviewer for cancer research grant proposals for the Congressionally Directed Medical Research Program and as a Spore Grant Review panelist for the National Cancer Institute. He has served as moderator of several online cancer patient forums and is a former member of the Board of Directors of the Kidney Cancer Association.

A portion of his survivorship story appears in the Summer 2017 edition of AACR's [Cancer Today Magazine](#).

