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## My Wife's Cancer Yields Lessons for Health Care: David H. Klein

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*By David H. Klein*

Dec. 24 (Bloomberg) -- In July 2008, my wife Linde was diagnosed with advanced squamous cell carcinoma of the oral cavity. Her subsequent treatment has led me to view U.S. medical care from a different perspective. What Linde and I have learned over the past two years has broadened my fundamental beliefs about medicine. In sum, while amazing advances have been made and miracles are occurring, medicine remains very much an art.

I've spent almost 40 years on the business side of the health-care industry, including the last seven as chief executive officer of a health plan. I believed my network of contacts would serve us well. I presumed there were unambiguous answers to questions about the best treatment plan and the best providers.

What I learned was that for uncommon diseases like Linde's, if not all diseases generally, clear answers often don't exist. I will never forget one doctor telling me that the information I sought wasn't available and that I would have to trust my gut. This is pretty incredible when you think about how much as a society we spend on health care.

The new federal health-care reform law promotes the adoption of health-information technology and supports comparative effectiveness research to understand the marginal contributions of new drugs, devices and procedures. But what we learned with Linde's treatment is that data on innovations, especially for less common diseases, isn't sufficient to broadly create evidence-based medicine.

### Risk Adjustments

Often medical research, even when coordinated and summed across the industry, doesn't have enough patients suffering with a particular disease to test alternative treatments using scientific -- trial and error -- methods. I can't tell you how many times I heard from physicians that every patient is different.

The same deficiency exists for assessing a practitioner's expertise with a particular treatment for a disease. To evaluate a doctor or treatment, it's necessary to risk adjust for differences in patients. Generally, it's more challenging to care for an older patient than a younger one. Similarly, treating patients with diabetes is more difficult than those without. There are myriad risk factors and standardizing for them is difficult if not impossible.

This has implications for what we consider the best places to receive care and how doctor performance should be reported. We really don't want clinicians to avoid riskier cases to achieve better grades.

## Work in Progress

In the face of these limitations, clinicians often rely on their understanding of underlying disease processes to decide the best course of action. Leading medical organizations convene panels of experts to provide opinions about the most effective approach for diagnosis and treatment. The work of these panels is important, but sometimes their opinions are later found to be wrong.

The recently developed human genome provides promise for gaining disease process insight, but it's a work in progress. Bottom line, there isn't as much hard science as one would like.

So, what do we do? I wish there was an answer that offered real value. After all, I'm a business executive who runs a health plan providing benefits to thousands of employers. I'm also a taxpayer who supports government programs. Unfortunately, there are no such assurances, but there are steps we can take.

## Best Course

As a society, we need to be honest about treatment limitations. Patients should be well informed about what the industry knows and doesn't know. There should be candor about the likelihood that care will make them worse instead of better. Patients should be empowered to be the treatment decision makers.

In recognition of the uncertainty patients face, we need to compassionately acknowledge their pain and fear. We need to counsel that aggressive intervention isn't always the best course of action.

I share these conclusions not to suggest dissatisfaction; Linde and I are grateful for her care. Her clinicians included the country's most respected doctors who did what they were trained to do -- aggressively seek a cure.

Rather, these observations are offered to challenge the U.S. health-care industry to be more explicit about medical treatment being as much an art as a science and to provide emotional and spiritual support to improve patient and caregiver experience.

## Course of Disease

There may be an economic benefit to this. As patients learn more about the limits of medicine, some may choose less intensive and costly care. As a nation, our health-care spending increases as patients near the end of life.

Since its onset, Linde's cancer has come back twice. The first time, she continued a courageous and valiant fight. The second time, she learned that further treatment would be painful, risky and probably leave her partially disabled and deformed. She was further told that the likelihood of having an extended, high quality life was remote.

With this knowledge, she opted for palliative care favoring quality of life over extending life. My acceptance of her decision, while difficult, was the best way I could show my love and support.

Linde commends her clinicians for being great teachers. They were candid, patient, used non-clinical terms, and shared their uncertainty about the effectiveness of suggested treatment. Their support of her as the decision maker was wonderful.

Linde and I have opted to share our journey because we hope the understanding of medicine we have developed will be helpful to others.

(David H. Klein is president and chief executive officer of Excellus BlueCross BlueShield in Rochester, New York. The opinions expressed are his own.)

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