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Positive Attitude

The First Step to Living Long and Well with Kidney Disease

Rebuilding a life altered by kidney disease can be a burden—or a challenge. Which way patients view their situations has tremendous implications for how successfully they will adapt. Therefore, a positive attitude is the first step in living long and living well with kidney disease.

THE “5 E’S” AND BEYOND

In 1993, Life Options introduced the revolutionary idea that “rehabilitation” for kidney patients meant returning them to their highest possible level of functioning. This required interventions in five key areas: Encouragement, Education, Exercise, Employment, and Evaluation.

Through research, patient contacts, and expert input from the Life Options Rehabilitation Advisory Council (LORAC), Life Options has focused this concept and made it exquisitely specific: kidney patients must be partners in their care—in fact, they must become *experts* in their own care.

Recent Life Options research supports the importance of patients’ active roles in their care. Both knowledge of kidney disease and performance of self-management strategies have been associated with patients’ improved physical and mental health functioning.^{1,2}

Life Options now believes that, in addition to the 5 E’s, three behavioral goals must be reached for patients to live long and well with kidney disease:

- Developing a positive **ATTITUDE** that supports active involvement
- Getting **ANSWERS** that will help them self-manage effectively
- Taking **ACTION** on their own behalf

Achieving these behavioral goals requires a new paradigm for kidney patient education that places health information in context. How? By giving patients hope for the future and a defined role in their own care. When patients embrace the potential for a good life, a positive attitude is

(continued on page S8)

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Message from the LORAC Chair

Since 1993, Life Options has sought to understand why some patients with kidney failure survive—and thrive—for decades, while so many others do not. Many of the roads to long-term survival seem to be paved with patients’ active involvement in their own care.

This issue of the *Renal Rehabilitation Report* (RRR) is the first of three focusing on patients’ roles in their own care. Encouraging patients to be active and involved will change how we teach them. Putting information in context by offering hope and teaching patients how to partner with us can make our efforts—and their lives—more fulfilling.

My 5-year tenure as LORAC chair has been exciting, productive, and rewarding. I have seen

nephrology practice change to embrace rehabilitation, and seen the difference it makes in patients’ lives. As I become an Emeritus, I turn the Chairmanship over to the capable hands of Bryan Becker, M.D. My heartfelt thanks go to Amgen for their generous, long-term support of the unique and important Life Options Program.

Derrick Latos, MD, FACP, of Nephrology Associates, Wheeling, WV, is chair of the LORAC, and serves on the boards of directors for the Mid-Atlantic Renal Coalition (ESRD Network 5), and the Forum of ESRD Networks. Serving as the nephrology representative, he also is Vice-Chair of the ACP-ASIM Council of Subspecialty Societies. To obtain Life Options materials, visit the Life Options website at www.lifeoptions.org or call (800) 468-7777. ♦

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Renal Advances™
In it for life

From Diagnosis to Dialysis Kidney School™ Helps Patients Cope with Kidney Disease

Kidney failure is a life-altering experience. Not surprisingly, people affected by kidney disease encounter a wide range of emotions—sadness, anger, fear and uncertainty about the future, even depression. Learning to cope with these feelings is crucial.

Explains Dr. Paul Kimmel, a nephrologist at George Washington University Medical Center, “How patients cope with the various aspects of kidney disease determines whether they are happy or sad, whether their family situations are functional or dysfunctional, and whether they are rehabilitated or disabled.”

Effectively dealing with the emotions of kidney failure is important, but it isn't easy. That's where Life Options Kidney School™ can help.

ABOUT KIDNEY SCHOOL

Kidney School is an on-line, interactive learning center that can be accessed free, 24 hours a day, at www.kidneyschool.org. Kidney School is designed to inspire, motivate, and empower people with chronic kidney disease and kidney failure to take an active role in their healthcare—and to improve their chances of living long and living well.

Kidney School consists of 16 interactive modules, addressing a wide range of topics, from exploring treatment options and anemia to vascular access care and understanding lab tests.

Module 5, “Coping with Kidney Disease,” deals directly with the emotional aspects of kidney disease. Topics include the typical stages of adjustment, practical strategies for coping, and resources for assistance.

UNIQUE STRUCTURE

Throughout the “Coping” module, the stages of adjustment to kidney disease are likened to the different rooms of a house—each with distinct features and characteristics. These “coping rooms” include:

- The Red Room (Crisis)
- The Empty Room (Isolation)
- The Woodshed (Anger)
- The Blue Room (Depression)
- The Workshop (Rebuilding)

This unique structure helps to illustrate that each room in a patient's “emotional house” has a particular purpose in helping that patient develop the knowledge, skills, and motivation to cope with kidney disease and live a full, enjoyable life.

FROM INFORMATION TO ACTION

As with all Kidney School modules, “Coping with Kidney Disease” is self-paced, so users can work at whatever speed they like. Brief pre- and posttests help users identify their informational needs and progress.

Throughout the module, practical tips and quotes from patients help users begin to develop their own coping strategies (see *Coping with Crisis: A Closer Look at Kidney School Strategies*, for some examples).

In addition, users can confidentially provide information about their own experiences, goals, and challenges. At the end of the module, this information is generated into a *Personal Action Plan*, a step-by-step guide for setting and achieving goals.

A TOOL FOR COPING

Kidney School can be a valuable tool for helping people recognize, understand, and effectively cope with the complex emotions that often accompany kidney disease and its treatment. Doing so can help patients stay on course with their treatment plan, maintain important relationships and activities, and optimize their overall quality of life. ♦

Support the Life Options Rehabilitation Program!

Life Options is administered by the Medical Education Institute, Inc. (MEI), a non-profit private foundation dedicated to helping people with chronic disease learn to manage and improve their health.

If you like the *Renal Rehabilitation Report*, and other Life Options materials, tell someone you know: your co-workers, friends on dialysis, chronic kidney disease patients, Amgen sales representatives, or others!



Coping with Crisis

A Closer Look at Kidney School™ Strategies

Understandably, many patients enter a state of crisis after being diagnosed with kidney disease. While some people are relieved to have a diagnosis, common emotions in this stage include sadness, fear, confusion, and the sense of being overwhelmed, numb, or hopeless.

The best way out of the crisis stage is to get answers. Information about what to expect can help patients see that life will be different, but it can still be good. Here are some tips for patients coping with crisis:

Consult the experts

Your healthcare team can answer questions and help ease your fears. Social workers, mental health counselors, and clergy or spiritual leaders can help you cope.

Find comfort and support

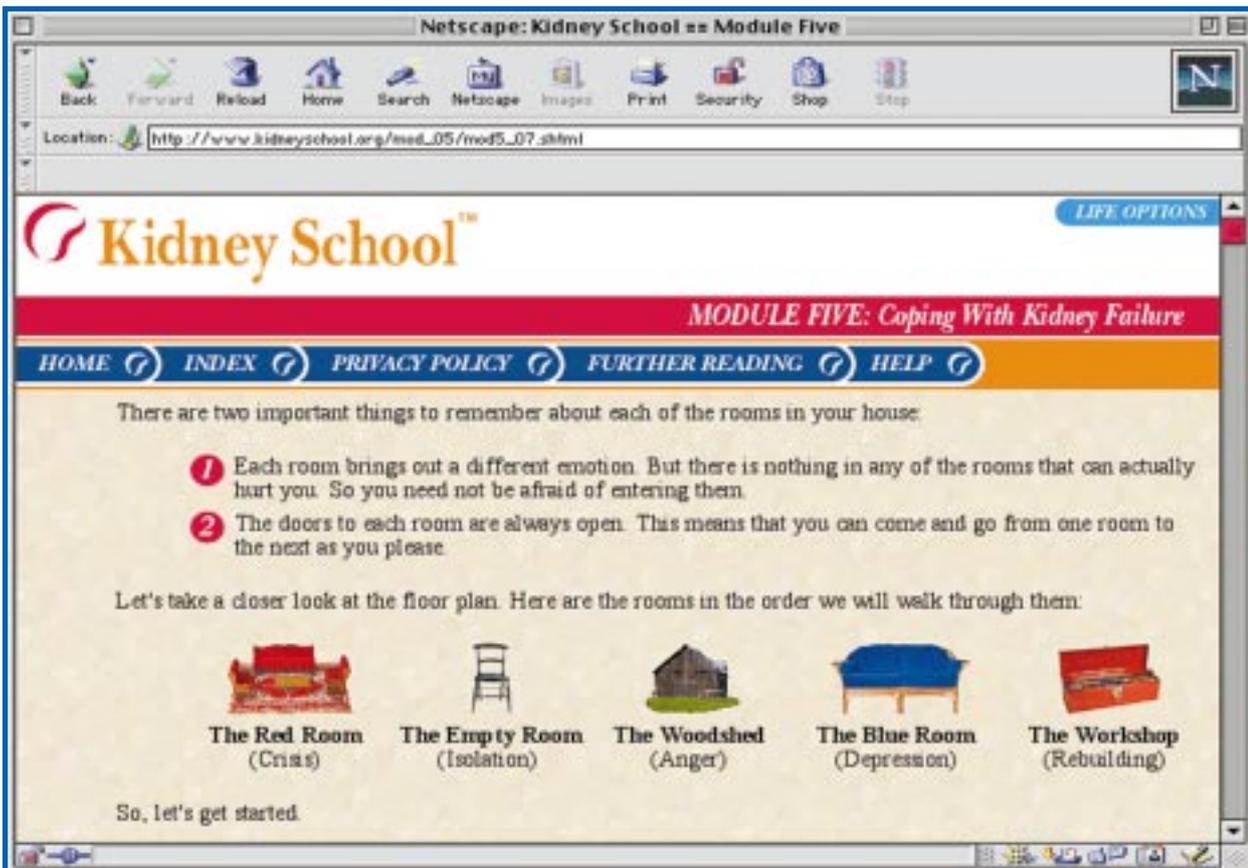
Surround yourself with people who care about you. Don't be afraid to ask for help—the sooner you do, the sooner you can begin to feel some relief.

Talk to people who have been there

Check to see if your medical facility has a patient mentor program or if there are kidney support groups in your area. Join groups such as the National Kidney Foundation and the American Association of Kidney Patients.

Learn to use the Internet

Whether at home or at the library, learn to surf for information. Explore Internet support groups, where members share advice and experiences through e-mail. ♦



Attitude, Answers, and Action

Positive Outlook Overcomes Challenges

“Kidney disease is not the focus of my life... I refuse to let it define me.”
—Robin Titterington

Like most people with kidney disease, Robin Titterington has faced more than her share of challenges. Still, the 47-year-old insists that while the illness has affected her life, it hasn't altered who she is.

“My priorities and values haven't changed,” says Robin. “I'm still the same person.” For Robin, focusing on the positive, finding valued support, and seeking information has allowed her to take a proactive approach to her treatment—and her life.

A COMPLEX HISTORY

Robin is not new to chronic illness. “I was born with spina bifida and have always had problems with my kidneys,” she explains. “One of my kidneys was removed when I was 19. That same year, I had a severe reaction to an antibiotic and became deaf.”

In 1988, at age 33, Robin's second kidney failed and she began hemodialysis. Less than a year later, she received a transplant that lasted nearly 9 years. She has been back on dialysis for almost 5 years.

Despite her medical conditions, Robin has never lost sight of her goals. “I earned my Master's degree from New York University and went on to work for the Georgia Division of Rehabilitation Services for almost 20 years,” she explains. “I also worked as an adjunct instructor at my local community college.”

Robin retired on disability in 1998, about one year after returning to dialysis. Yet she continues many of the activities she enjoys, such as cheering for the Atlanta Braves and caring for her dog and two cats, whom she refers to as the “fabulous furrries.” She stays busy with volunteer work, travel, reading, and church activities.

Q&A

ASK THE EXPERTS: PSYCHOSOCIAL FACTORS IN KIDNEY DISEASE

An Interview with Paul L. Kimmel, MD
Nephrologist, Internist, and Professor of Medicine
George Washington University Medical Center, Washington, DC

Q *What are the most important psychosocial factors related to kidney disease?*

A It's important to look at each patient as functioning and embedded in many different relationships—as an individual, in a family, in the dialysis unit, in an occupation, and in the larger social world.

The importance of a factor depends on what one wants to evaluate. For example, if you're looking at the patient alone, you might look at personality or mood. If you're looking at the patient in the context of a dialysis unit, you might consider satisfaction with care, interaction with staff and other patients, and level of compliance. In terms of family, you might look at interaction with family members and family function.

In general, when trying to determine how patients are feeling, important factors include functional status, perceived burden of illness, satisfaction with life, perceived quality of life, mood or level of depression, and

perceived social support, including satisfaction with marriage, family, and care.

Q *How important is it for people with kidney disease to maintain a positive attitude?*

A An important concept is adjustment to illness, which probably is related to patients' perceptions of the burden or intrusiveness of illness. Imagine two elderly patients who are blind, diabetic, have had an amputation, are relatively homebound, get assistance with food, and are transported to and from dialysis.

One might say, “I'm miserable—I don't get to do anything, and I'm dependent on others.” The other might say, “It's not so bad—dialysis gets me out of the house, and I like how the nurses take care of me.” These two patients are likely to have radically different scores on illness perception scales—and might have different survival.

The reasons are not clear, but evidence suggests that how patients view their illness—some might call it perception or ability to cope—is associated with different outcomes. This relates to many psychosocial parameters, including social support, level of depression, and satisfaction with life.



MAKING THE TRANSITION

While Robin has adjusted well to life with kidney failure, she admits the initial transition was difficult. “When my kidney failed, I had just started my job as director at the Georgia Interpreting Services Network, and I was working for my professional mentor,” she recalls. “I wanted so badly to do well.” In addition, Robin had bought a house and hadn’t yet worked long enough to receive disability. “It was a difficult time,” she says. “I think, honestly, one thing that kept me going was that I felt I had no choice.”

How did Robin make it? From the start, her healthcare team was a source of education and support. “They gave me the information I needed and answered all my questions,” she explains. “They also made it clear that I had responsibilities too—that there was only so much they could do.”

Over the years, Titterington has also found comfort and strength among her family, friends, and church community.

“They are definitely my support system,” she says. In addition, Robin believes in learning from others. “The Dialysis Support e-group (e-mail dialysis_support-subscribe@yahoo.com) has been a lifesaver, since communication at the unit is difficult for me,” she says. “A similar group, the Association of Late-Deafened Adults, has helped me with my hearing loss.”

STAYING POSITIVE

Like most people, Robin still has her ups and downs. When things get difficult, she relies on a time-proven approach: focusing on the positive. “Hugging a friend (or a furry friend!) helps and so does getting a good night’s sleep,” she says. “Things usually look better in the morning.”

While Robin says her life with kidney failure is good, she admits it’s not without compromise. “Given a choice, I’d still be working,” she explains. “I really loved working, but I love my volunteer work too.” *(continued on page 59)*

Q *What can physicians do to help patients maintain a positive outlook?*

A There are very interesting data to suggest that patients’ satisfaction with their nephrologists is associated with increased compliance and high levels of serum albumin.

Such data suggest that if we can devise interventions to improve patients’ satisfaction with their nephrologists, we might be able to improve nutritional status and compliance, both of which have been associated with improved morbidity and mortality. It behooves doctors to be aware that their image, and, potentially their behavior, may have a profound impact on patient outcomes.

Q *What symptoms should alert patients and clinicians that depression may be present?*

A Many symptoms of depression are similar to those of uremia—fatigue, changes in mood, level of interest or pleasure, ability to concentrate, changes in appetite or weight, and inability to get a good night’s sleep. Things that differentiate depression from renal disease include feelings of guilt or worthlessness and preoccupation with thoughts of dying.

Physicians can enhance their detection of depressive disorders by routinely asking patients how they’re feeling and following with questions, such as ‘So, it’s been a rough week?’ or ‘You’re anxious because of the stress of getting all the work done in the house and keeping up with the dialysis schedule?’ Such open-ended questions show patients that you want to understand their situation and are receptive to conversations about symptoms related to depression.

Q *What can physicians do to improve patients’ psychosocial outcomes?*

A Physicians must provide care for the physical aspects of kidney disease and help patients cope with the stress of kidney disease and its treatment. They can be vigilant about assessing their patients’ mood, and also understand how to diagnose depression.

In addition, physicians must appreciate patients as functioning in many contexts. The ways in which patients interact with doctors, nurses, and technicians in the unit can be as important as the ways in which they interact with families, friends, and others at home, at work, and in their communities. ♦

Positive Attitude

The First Step to Living Long and Well with Kidney Disease

(continued from page S1)

likely to follow. In turn, this attitude will facilitate information-seeking—getting answers to be able to take action.

ATTITUDE: A LIFE AND DEATH MATTER

How positively patients feel about their lives with kidney disease appears to play a key role in their ultimate outcomes. The mental component summary (MCS) subscale of the MOS SF-36 measures patients' views of their own role functioning, mental health, and emotional well-being.

Higher MCS scores have been shown to be a powerful and independent predictor of lower mortality and hospitalization in retrospective and prospective studies.^{3,4,5,6} Conversely, low MCS scores have been associated with depression,³ which, in turn, is associated with an increased risk of death.⁷

Therefore, helping patients to feel more positive about their lives and their futures is essential—and patients' MCS scores can help indicate whether our efforts are having the desired effect.

FIRST COMBAT FEAR

People who learn that their kidneys are failing—whether for the first time or after a kidney transplant—are anxious and *afraid*.⁸ They may be afraid that their changed lives will not be worth living. They may be afraid that they will

become dependent on their loved ones for care, or not be able to contribute in the same ways to their families. They may be afraid that they will die.

Fear and anxiety may interfere with learning. Fear triggers the fight-or-flight reaction in the human body.⁹ Adrenaline is released, the heart races, arterial blood pressure and blood sugar increase—and learning complex new information becomes difficult.^{10,11} Hans Selye, the father of stress research, said, “adopting the right attitude can convert a negative stress into a positive one.”⁹ Therefore, helping people with kidney disease begin to form positive attitudes must begin by identifying and addressing their fears, and offering reassurance, support, and counseling if needed.

POSITIVE ATTITUDE AND HOPE

Weil (2000) examined hope among people with kidney failure, noting that in chronic diseases, including kidney disease, hope is associated with social support, religious beliefs and spirituality, and maintaining control.¹² The author noted, “hope, when combined with a feeling of control over their treatments, decreased the stress associated with chronic hemodialysis.”

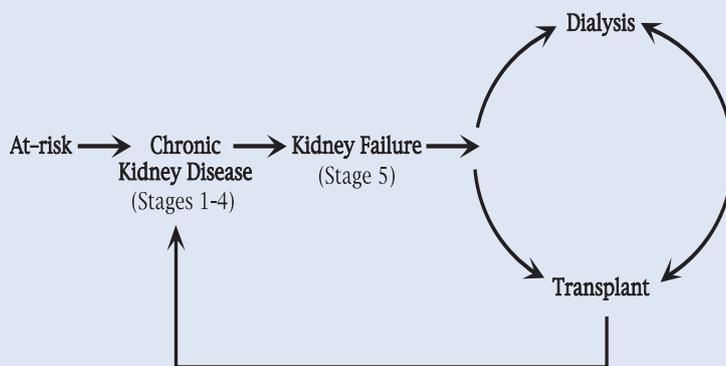
Other researchers have observed that hope is both a coping strategy and an outcome.¹³ These observations appear consistent with key findings of the Life Options

Patient Longevity Study, which identified a core set of “affirmations” held by long-term dialysis survivors:

- Self identity: “I am still me.”
- Self preservation: “I want to live.”
- Self efficacy: “I am in control.”
- Self worth: “I am still valuable.”¹⁴

We know that patients who successfully adapted to the challenges of kidney failure made these affirmations. Encouraging other patients to hold these beliefs earlier in kidney disease may help them to have positive attitudes and to live longer. Renal professionals, family members, and patients can encourage these beliefs and work to achieve them.

Life Options Kidney Disease Cycle



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CREATING POSITIVE CHANGE

Helping kidney patients to develop positive attitudes that will support their getting answers and taking action to become experts in their own care is key to their long-term outcomes. The last *Renal Rehabilitation Report (RRR)* introduced the Life Options Kidney Disease Cycle (left). This diagram represents the concept that all stages of kidney disease and its treatments are part of a single, continuous process. From chronic kidney disease (CKD) to dialysis and transplant and back again, kidney patients are all members of the same group.

To thrive at every stage of kidney disease, patients need to believe that their illness is not the end of their lives, that they are strong enough to meet the challenges, and that they can produce positive outcomes for themselves and their families. By supporting positive attitudes, professionals can help patients take the first step toward creating fulfilling lives. ♦

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Positive Outlook (continued from S5)



Robin Titterington in Hall Tyrol, Austria—August 2001

Staying positive is essential as people face the many challenges of kidney disease. For Robin, this has meant focusing on the good, surrounding herself with support, and finding the information she needs to make the best choices for her treatment and her life. She feels these strategies can help other patients as well. “It’s important to learn all you can and know that you are in control,” she advises. “Follow the diet and guidelines for care, never miss a treatment—and enjoy the good times.”

As Robin has shown, the results can be inspiring. “Kidney disease is not the focus of my life,” she explains. “I refuse to let it define me.” ♦

Making the Most of Education and Support CKD Patient Looks with Hope to the Future



From coping with the diagnosis to preparing for dialysis or transplant, life with chronic kidney disease (CKD) can be full of challenge and uncertainty. However, as 64-year-old

John Mudie has shown, with the right information, support and approach, life with CKD can be fulfilling and enjoyable.

GRADUAL CHANGE

For John, it took time for the reality of kidney disease to set in. During a routine check-up in 1998, tests showed he had an elevated creatinine level. Two years later, he was referred to a nephrologist. “At that point, I wasn’t overly concerned,” he says. “It was more of a nuisance than anything.”

As his creatinine level rose steadily, John took his doctor’s advice 6 months later and visited a dialysis unit. That’s when everything changed. “I saw no happiness or joy,” he says. “The people in the chairs didn’t seem to be alive. I thought ‘Oh my God! This is what I have to deal with?’ That’s when I began to take it seriously. That’s when I got motivated.”

For John, a former college professor, getting motivated meant learning about all aspects of kidney disease and its treatment. To start, John reviewed the written materials from his healthcare team. It was speaking with a peritoneal dialysis nurse, however, that he found most helpful. “Her coaching was invaluable,” he says. “She gave me insight into the importance of diet and exercise and the various treatment options, including transplant.”

John has also made use of the Internet, both by surfing for medical information and as an active member of several e-mail dialysis lists. “There’s a lot of practical information out there,” he explains. “I’ve seen messages from people who’ve been on dialysis for 30 years. It helps to know that others have been there and survived.”

THE VALUE OF SUPPORT

John knows that, while information is important, so is support. This is a lesson he learned in coping with two other chronic conditions—bipolar disorder and alcoholism.

“Over the years, support groups have taught me a spiritual approach to life,” he says. “They’ve shown me the danger of denial, the importance of taking responsibility for myself, and the value of connecting with others.”

John believes the same is possible for his experience with kidney disease. “I’ve become a member of the AAKP,” he says. “I’ve received their literature, and I’ve asked for their help in starting a local support group.” Armed with information and support, John has been able to adopt a proactive approach to living with CKD. “I’ve learned to ask questions,” he says. “And, I get copies of all my labs.”

MOVING FORWARD

John has also begun working on a strategy for his treatment. “I’d like to start out on hemodialysis, get that working, and then try PD,” he explains. So, he recently had a fistula placed in his arm as preparation for hemodialysis.

John currently works part time with the mentally ill. He is also taking classes at his local community college. “I have always enjoyed computers—from programming and software, to assembling and, most recently, web page design,” he says. “My latest hobby, though, is kidneys. It takes a lot of energy to learn to live with the various aspects of kidney disease.”

As for now, John’s creatinine level continues to rise, he reports feeling exhausted, and his list of medications is so complex, he now carries it in his Palm™ Pilot. Still, he manages to keep his life in perspective.

STAYING POSITIVE

“A while back, I was going through a particularly tough time,” John says. “I was feeling miserable, but my experience told me that kidney disease had to have a gift for me somewhere.” One day, that gift became apparent. “I got stuck in traffic, looked around, and thought, ‘This is so wonderful! I am enjoying this moment.’” he recalls. “I had learned to enjoy just what was happening around me, even being stuck in traffic.” According to John, that simple experience had a profound and lasting effect. “Before I was diagnosed with kidney disease, I was busy being busy,” he says. “Now, I’ve come to enjoy life—to realize just how precious it is. That, for me, is the gift of kidney failure.” ♦