

# THE PatientCitizen

IMPROVING OUR LIVES THROUGH EMPOWERMENT

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## Patient Ambassador Profile: Todd Martin

When 38-year-old Todd Martin was diagnosed with chronic kidney disease (CKD) in 1988 as a result of focal glomerulo sclerosis, he sought to learn all he could about the disease that would change his life. With the help of his physicians, Todd was able to control his kidney disease for several years by making some changes to his lifestyle; however, in February of 1991, his physician informed him that his CKD had progressed to end stage renal disease (ESRD) and that he would need to begin dialysis right away.

Today, Todd lives in Middletown, OH and receives treatment at his local dialysis facility three times a week. Since Todd was diagnosed with ESRD, he has received hemodialysis, peritoneal dialysis and a kidney transplant which he believes gives him the ability to identify with many patients in the dialysis community.

Todd first learned of Dialysis Patient Citizens while studying at Wright State University in Dayton, OH. A nurse that worked at the University and knew Todd well told him about the organization and encouraged him to start participating as a Patient Ambassador. She believed that Todd had the type of personality that could be an inspiration to other dialysis and pre-dialysis patients. Eager to better himself and those around him, he made the decision to join Dialysis Patient Citizens and became a Patient Ambassador in January of 2008.



Todd Martin

As a Patient Ambassador, Todd has taken on many patient advocacy roles including participating in local dialysis days and kidney disease prevention events, traveling to Washington, D.C. for World Kidney Day and writing to state and federal lawmakers about important policy issues affecting kidney disease patients. Most recently, Todd testified at an Ohio Senate Finance Committee hearing on the impact of dual-eligibility cuts to Medicaid. Speaking on behalf of the 14,000 people in Ohio who rely on dialysis for survival, Todd explained how provider reimbursement cuts could have a disproportionate impact on patient access to care.

In addition to his work as a Patient Ambassador, Todd works as a physi-

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DPC is a 501(c)(4) non-profit organization governed by dialysis patients.

## President's Message: Changes to the DPC Board of Directors



Nancy Scott, Board President

Over the last few months, the Dialysis Patient Citizens Board of Directors has experienced some big changes. DPC lost a dynamic Board Member and great friend, Bev Schroeder, in April and will welcome two new Members to the Board this fall.

### DPC Mourns Loss of Board Member Bev Schroeder

In April, DPC Board member and long-time kidney patient advocate Beverly "Bev" Schroeder passed

away at the age of 76. A dialysis patient since 2004, Bev will be remembered as a living example that people who suffer from kidney failure can live a full and rewarding life. She inspired dialysis patients to take control of their kidney health and to be grateful for life-saving dialysis care.

Bev joined DPC in 2004 and was elected to the Board of Directors in 2006. She was chosen to be Secretary of the Board in August 2010.

Bev believed that being an advocate came naturally to her. With her passing, the dialysis community and DPC have suffered a great loss. Bev was an active member of the DPC Board of Directors, and her involvement and contributions to DPC were inspirational. She will surely be missed.

### DPC Welcomes New Board Members

As Board President, I would like to extend a warm welcome on behalf of the entire organization to DPC's two newest Board Members, who will begin serving their terms in September.

Christina Esposito, of Belle Harbor, NY, has been on dialysis for more than 20 years in between four kidney transplants. She joined DPC as a Patient Ambassador in July 2009 and was chosen as the New York State

Ambassadors Coordinating Together (ACT) Team Leader in May 2010. Christina is very active in her community and with DPC, fighting to bring about positive change and make a difference in the lives of kidney disease patients.

DPC would also like to welcome Carol Thomas, from Sacramento, CA, to the Board of Directors. Carol has been an in-center dialysis patient since 2007 and a Patient Ambassador since 2009. Carol has been an extremely active DPC member: participating in Washington, DC fly-in events, leading the Northern California ACT team, and encouraging other patients at her center to join the organization. As an ESRD patient, Carol understands the concerns of others who rely on dialysis treatments and has devoted her life to helping others.

DPC is proud to welcome Christina and Carol to the Board of Directors and we look forward to continuing our work with them in the future.

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cian's assistant at the University of Cincinnati, educating medical students on dialysis. He also volunteers for "Tackling the Organ Donation Dilemma" and is a Gospel minister, church Elder and youth leader.

Todd devotes his time to assisting patients through their transition onto dialysis and is a living example that dialysis patients can have full and inspirational lives. A passionate and determined "life-long learner" and

educator, Todd has dedicated his life to assisting and educating members of the dialysis community and others about kidney disease and to spreading awareness about these important issues.

## Learn About Diabetic Foot Ulcers

Diabetic foot ulcers (DFUs) are chronic sores that can develop on the foot or lower extremities of people with diabetes, a condition in which blood sugar levels are abnormally high.

An estimated 26 million people in the U.S. have diabetes<sup>1</sup>, and among those, approximately 15 percent will develop a DFU in their lifetime<sup>2</sup>, and approximately 2.5 percent develop a DFU each year.<sup>3</sup>

DFUs often begin as relatively minor sores or cuts that can get worse because of complications of diabetes—specifically, peripheral neuropathy, a condition in which feeling, or sensation, is lost due to reduced blood flow to the lower extremities.

This loss of feeling can prevent a patient from noticing injuries, including:<sup>4</sup> sores caused by repetitive minor trauma (such as long walks); wounds caused by a single trauma (like scraping your foot, stepping on rocks, putting your feet in hot water, cutting your toenails incorrectly, wearing shoes that don't fit properly); and foot problems (such as calluses and hammertoes).

These injuries can quickly turn into DFUs, and if not treated properly, may not heal and may become infected. This can lead to serious complications, including toe, foot, or even leg amputation. In fact, of those patients who do develop a DFU, 14 to 24 percent

will require an amputation. However, DFUs can often be more easily treated if caught early, so regular foot examinations are critical to helping diagnose any problems early on.

It is especially important to monitor for any injuries to your feet that you might not feel. Potential problems to look for include: scrapes, calluses, blisters, sores, redness and red spots, swelling, toenail infections, etc.

Have your feet professionally checked regularly—just like your eyes and your kidneys—and if a DFU does develop, see a wound care specialist immediately.

Your wound care specialist will develop a personalized treatment plan that may include the following:

- Treating any existing infection with antibiotics or topical treatments.
- Removing the dead or unhealthy skin around your wound, called debriding. This process helps clean the wound and should only be done by a qualified medical professional.
- Applying specialized dressings and other treatments that promote healing. Different wounds require different kinds of dressings, so your doctor will determine which is best for you and provide instructions for their proper care. Advanced wound care products may be recommended to help

encourage faster healing.

- Offloading your wound, which means taking weight and pressure off of your foot, and most importantly, off of your wound.

Heal2gether is a community health education program that uses education and action to foster awareness about DFUs—what they are, why they need to take special care of their feet, how to identify early warning signs, and the importance of seeking treatment from a wound care specialist immediately. For more information on DFUs, Heal2gether, or to find a wound care specialist in your area, please visit [www.heal2gether.org](http://www.heal2gether.org).

1. Centers for Disease Control and Prevention. 2011 National Diabetes Fact Sheet. Available at: [http://www.cdc.gov/diabetes/pubs/pdf/ndfs\\_2011.pdf](http://www.cdc.gov/diabetes/pubs/pdf/ndfs_2011.pdf). Accessed February 18, 2011.

2. American Diabetes Association. Consensus Development Conference on Diabetic Foot Wound Care. *Diabetes Care*. 1999;22(8):1354-1360.

3. Sheehan P, Jones P, Caselli A, Giurini JM, Veves A. Percent change in wound area of diabetic foot ulcers over a 4-week period is a robust predictor of complete healing 12-week prospective trial. *Diabetes Care*. 2003;26(6):1879-1882.

4. American Diabetes Association. Consensus Development Conference on Diabetic Foot Wound Care. *Diabetes Care*. 1999;22(8):1354-1360.

5. *Ibid.*

## Fighting for Our Patients' Rights in Health Insurance Exchanges

The health insurance reform legislation that was signed into law in March 2010, known as the Affordable Care Act (ACA), made many important changes to our nation's health insurance system. One of the largest re-

forms that will go into effect in 2014 is the creation of new state-based health insurance exchanges. These new insurance marketplaces are designed to expand health insurance coverage by increasing options for consumers.

As one of our priorities for the coming year, DPC is working to ensure the voice of dialysis patients is heard by policy makers as these important changes are implemented. There

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## Ask a Dietitian

Jeanette Morgan, MHA, RD, LD

### Losing Weight When You're on a Renal Diet



As if following a renal diet wasn't tricky enough already, now you have decided it is time to take off a few pounds.

How can you go about it and keep up good lab values at the same time? Since kidney transplant programs often recommend weight loss prior to making you active on the transplant waiting list, this can be a big concern for many dialysis patients. Well, this issue's article is going to review some of the major points to keep in mind as you to try to lighten up!

- 1. Protein.** It is very important as you reduce your calorie intake to make sure that you still get enough protein every day. Losing muscle mass and having too little albumin in your blood does not put you in the best condition for transplant surgery, and it also does not help your body fight infections. Plus, high protein foods tend to keep you from becoming hungry for a longer time than foods high in carbohydrates. So be sure that this is not where you cut the most calories. Include high protein foods such as eggs, chicken, fish, and lean red meat in your diet each day. In addition, if you normally use a protein supplement that is high in calories, such as canned drinks, talk to your dietitian about protein supplements that are lower in calories.
- 2. Fluid.** Many popular diets encourage you to consume large amounts of fluid (soups, diet drinks, juice, water, etc.) to help reduce hunger as you cut your calories. This is simply not a good idea for dialysis patients. Instead, use gum and sugar free hard candies to help you resist the urge to nibble during between meals.
- 3. Potassium.** Stay away from fad diets that encourage you to eat high potassium fruits or vegetables such as grapefruit, bananas, acai berries, noni juice, tomatoes, & vegetable juice. On the other hand, lower potassium fruits and vegetables can fill you up without adding too many calories. Review with your dietitian which fruits & vegetables make good lower potassium and calorie choices.
- 4. Meal and snack frequency.** Having a small meal or snack every 3 to 4 hours rather than going half of the day without eating can also help you minimize hunger when dieting. Just be sure that the meals & snacks are not too big or you won't end up cutting your calorie intake very much. Your dietitian can review portion sizes with you and will have information that can help you figure out the calories count in the foods you are eating.
- 5. Exercise.** Yes, that dreaded word! But it is true, regular workouts can help you lose weight and they will also help you feel better in general. Talk with your doctor and dietitian

about what types of exercise would be best for your individual circumstances. As an added bonus, if you are in good shape from regular exercise, you may also recover more quickly from transplant surgery.

- 6. Weight loss partners.** If there is someone in your life (a friend, significant other, relative, or even a coworker) who can begin a weight loss program at the same time as you, it can be a big help in staying motivated.

Losing weight is tough whether you are on dialysis or not. But with a little determination and dedication, it can be done even on a renal diet! Don't hesitate to ask for support from any of your caregivers at the dialysis clinic. Their words of encouragement may be the extra motivation that you need to reach your weight loss goals.

### HAVE A QUESTION

for a dietitian you think would be helpful to kidney patients and would like to see it published in the Patient Citizen?

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are a variety of areas where DPC is focused on raising awareness and ensuring that dialysis patients are protected under the new health insurance exchanges.

In May, DPC submitted a letter to the Center for Consumer Information and Insurance Oversight (CCIIO) urging CCIIO to consider the needs of people with kidney failure who are on dialysis when designing the

framework for the health insurance exchanges. CCIIO, housed within the Centers for Medicare and Medicaid Services (CMS), is the department charged with helping implement many provisions of the Affordable Care Act and it oversees the execution of the provisions related to the private health insurance exchanges.

In the letter, DPC highlighted the need for dialysis services to be considered an essential health benefit in the new exchanges, ensuring that every health plan in the new system will assure coverage of dialysis treatments. DPC urged that the subsidies and financial assistance for purchasing health insurance through the exchanges be offered to dialysis patients and that exchange plans include an adequate choice of providers. DPC also requested uniformity between coverage inside and outside of the exchanges,

meaning patients would be allowed to keep the health plans of their choice for the statutory 30-month period before Medicare becomes their primary payer (known as the Medicare Secondary Payer law).

If you would like to read the full letter, you can find it on our website at <http://www.dialysispatients.org/advocacy>.

DPC, along with others from the kidney community, also met with staff from CCIIO to discuss these concerns.

Since our issues were not explicitly addressed in the recent guidelines released by CCIIO, we will continue our outreach efforts and may need to ask for your help. To ensure you receive our timely updates and 'calls to action', please make sure we have your email address by registering on our website: [www.dialysispatients.org](http://www.dialysispatients.org).

## CROWNWeb: The Future of Patient Data Management

An overview of the Centers for Medicare & Medicaid Services' efforts to improve patient care by reducing the time required for dialysis facilities to assess patient data.

By: Oniel Delva, BA

The Centers for Medicare & Medicaid Services (CMS) is currently developing an Internet-based data-collection system, known as CROWNWeb, to help reduce the time that it takes Medicare-certified dialysis facilities to analyze and compare clinical performance data by up to 75 percent. This reduction in time will, among other things, aid efforts to improve patients' overall quality of care by providing dialysis facilities with a more timely and accurate representation of the End Stage Renal Disease (ESRD) patient and provider population.

CROWNWeb is scheduled to be released for use by all Medicare-certified dialysis facilities in early 2012. While this system is not designed to be used directly by the ESRD patient population, the data contained in it may help empower patients to find better health care value and better health care quality, and help ensure appropriate patient access to care. After CROWNWeb is in full production for one year, it will begin to help enhance CMS' ability to provide dialysis patients with the means to make informed health-care decisions by integrating some of

CROWNWeb's facility measurement data with CMS' Dialysis Facility Compare (DFC) reporting results. DFC is an online tool that provides key facility data to individuals who have (or may develop) ESRD and their caregivers, allowing them to make educated decisions regarding treatment options. DFC provides information on nine facility characteristics and three quality measures for more than 3,500 dialysis facilities in the United States (available at [www.medicare.gov](http://www.medicare.gov)).

Additionally, CROWNWeb's ability to electronically collect and report clinical performance data for all individuals with ESRD may add significant value for facilities and for individuals who have or may develop ESRD in three ways:

1. Availability of performance reports –

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## State Round Up

With the exceptions of Alabama, Michigan, New York and Texas, most states' fiscal year began July 1, so by the end of June most states had finalized their budget for the 2012 fiscal year. While states have varying budgetary processes and policies to address shortfalls, there has been a common theme among states facing budget deficits: Medicaid cuts. These cuts generally take the form of Medicaid reimbursement cuts to providers, restrictions to Medicaid optional benefits for patients, increases in patients' Medicaid co-pays/premiums, and/or restrictions in the number of services Medicaid will cover. In addition, some states look to cut funding from state kidney programs, which provide supplemental financial aid and other benefits for patients that are ineligible for state Medicaid services.

DPC and other members of the kidney community worked hard to counter potentially devastating cuts and we will continue to do so as states finalize their budgets. Information about DPC's efforts at the state level is available on our State Advocacy and Resource page at <http://www.dialysispatients.org/patient-assistance-state-advocacy>. DPC has submitted comment letters, testified before committees and encouraged patients to contact lawmakers on these issues.



**Arizona:** The state has frozen enrollment of its "spend down," or medically needy program, and it will be eliminated effective October 1, 2011. The State is

awaiting on a ruling from the Centers for Medicare and Medicaid Services (CMS) as to the legality of the passage of a five percent reduction to provider reimbursement for patients who are solely covered by Medicaid as well as the elimination of coverage of non-emergency medical transportation services (NEMT) in Maricopa and Pima counties and the institution of co-pays in the State's other counties.



**California:** The state is awaiting a CMS ruling on the legality of a ten percent reduction to provider reimbursement for patients who are solely covered

by Medi-Cal. In addition, the State has instituted a seven visit cap on coverage for out-patient visits, an increase in Medi-Cal copays for patients and an elimination of Medi-Cal coverage of oral nutritional supplements. These cuts began on July 1, 2011. DPC has

asked for the oral supplement cuts to not impact dialysis patients. Additionally, Medi-Cal primary beneficiaries have been moved into managed care plans as of July 1, 2011.

**Georgia:** The State will reduce Medicaid reimbursement to health care providers by half of a percent. The State will also be increasing patient copays for Medicaid, effective July 1, 2011.



**Florida:** The State will be moving to state-wide managed care plans for Medicaid

beneficiaries over the course of next year. Additionally, the "spend down" program now requires patients to show payment of their medical bills to qualify.

**Indiana:** Indiana has gone to a rules notification system, so the State Medicaid department can implement reductions in coverage of patients or reimbursement to facilities without legislative approval.

**Kentucky:** The State is planning to move all ESRD patients into managed care organizations.



**Massachusetts:** The State is proposing an ESRD bundled reimbursement

system for providers for care to patients covered by Medicaid solely. The state MART transportation system has made great improvements for transportation for dialysis patients.

**Michigan:** The National Kidney Foundation of Michigan lost its funding to administer the State's kidney program.

**Minnesota:** The State has proposed a budget that would eliminate all Medicaid reimbursement to providers for care of patients with Medicaid as their secondary insurance.

**Missouri:** The State reduced its annual funding for the Missouri Kidney Program (MoKP) by \$1.5 million.



**Nevada:** The State will reduce reimbursement to health care providers by 15 percent for care of patients who are solely covered by Medicaid, effective July 1, 2011.

**New Jersey:** The State is proposing an ESRD bundled reimbursement system for providers for care to patients covered exclusively by Medicaid.



**New York:** Effective April 1, 2011, the State reduced reimbursement to health care providers by two

percent for care of patients who are exclusively covered by Medicaid. Additionally, DPC is awaiting a ruling on the elimination of Medicaid coverage of oral nutrition supplements. Reimbursement for non-emergency medical transportation (NEMT) was also lowered for transportation of dialysis patients. The State has assured DPC that patients will not be impacted by these reimbursement changes.



**North Carolina:** The State reduced Medicaid reimbursement to health care providers by two

percent for patients with Medicaid primary and secondary insurance.

**Ohio:** The State exempted dialysis providers for one year from any reimbursement rate reductions for care of Medicaid patients.



**Oregon:** The State reduced reimbursement by 11.2 percent for care of patients covered exclusively by Medicaid,

on a fee-per-healthcare service basis, effective July 1, 2011. Medicaid managed care plans will also see reductions, but it is unknown how much at this point.



**South Carolina:**

The State put into effect a three percent reduction to reimbursement to health care providers for care of patients covered by both Medicaid primary and secondary insurance, effective April 1, 2011. An additional four

percent provider rate cut to both primary and secondary Medicaid payments will go into effect on July 8, 2011.



**Texas:** The State passed a provider reimbursement rate cut of five to seven percent for care of

patients solely covered by Medicaid, effective October 1, 2011. The state Kidney Health Care (KHC) program had its budget reduced by \$4 million.



**Utah:** The State is seeking CMS approval to increase copays for Medicaid patients, and is proposing a bundled reimbursement system for care to patients covered solely by Medicaid.

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Facilities will be able to access clinical performance measure (CPM) reports six months after the data collection period ends (compared to the current two-year delay). This change is expected to help improve patient care efforts by providing a timely analysis of treatment trends and findings.

2. Elimination of randomly sampled data – CROWNWeb will allow facilities to report and access CPM data for 100% of their patients (compared to a historical 5% to 8% random sample). This will provide a better representation of the patient population, which should allow facilities to better focus on patient-specific needs.

3. Inclusion of new CPMs – Facilities

will be able to include data regarding patients' hospitalization, immunization, and infections with their CPM data. These new CPMs will work towards improving patient care efforts by further analyzing various factors that may impact treatment.

### More Information

Patients who want to obtain more information on the CROWNWeb system can visit the Project CROWNWeb website at [www.projectcrownweb.com](http://www.projectcrownweb.com).

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The author assumes full responsibility for the accuracy and completeness of the ideas presented. The author welcomes comments on the ideas presented; please send comments to [CRAFT@ProjectCROWNWeb.org](mailto:CRAFT@ProjectCROWNWeb.org).

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