

The Citizen Kadney

A publication of Dialysis Patient Citizens (DPC) Education Center



OUR NEW NORMAL



SARS-CoV-2 Antigen Rapid Test
(Self-Testing)

President's Message



Welcome to Dialysis Patient Citizens' 19th issue of *The Kidney Citizen*. Thank you for your unwavering support as DPC and the DPC Education Center continue to work for a better future for dialysis patients nationwide.

Every single day, patients across the US receive an End Stage Renal Disease (ESRD) diagnosis that changes their lives. Upon receiving the diagnosis, many patients enter a state of panic, confusion, or uneasiness about the future. However, with sufficient support and proper education about the disease, patients can rest assured that ESRD is manageable, and they can begin adjusting to their "new normal" on dialysis. ESRD is not a death sentence; on the contrary, it's an opportunity for patients to persevere through significant change and become even stronger.

When my doctor told me my kidneys were failing back in 2014, I immediately worried for my family, especially my daughter. I thought about my small business, and whether I'd have the strength to continue running it and pay for my expensive treatment.

There were obstacles – there always are – for every patient, no matter what. I experienced some problems with my treatment facility. The staff did not have the resources they needed to treat a surplus of patients. I noticed low staff levels at my center, with the technicians spread thin and tired. My access to care felt scarce, even in New York City. It was very common to move clinics, as there just weren't enough seats for everyone.

The challenges, while difficult, did not slow me down. DPC helped educate me on how to live healthily and happily with ESRD. I received dialysis treatment for two and a half years before receiving a kidney transplant in December of 2016. I did so while running a successful business and raising my exceptional daughter. Then came the COVID-19 pandemic, which proved all the more dangerous for me because I had to take immunosuppressant drugs as part of my post-transplant protocol. I needed the drugs to prevent my body from rejecting my new kidney, but the drugs exposed my body to dangers from the virus. But yet again, I prevailed.

With each step in the treatment process – beginning dialysis, preparing for transplant, receiving a transplant, and post-transplant care – I adjusted to a "new normal." Each new step brought specific challenges, but none that were insurmountable. DPC seeks to show kidney patients that with support and determination, they can create a new "normal" for themselves. Of course, ESRD patients' lives change forever upon beginning dialysis. Nevertheless, they don't have to change for the worse. Through DPC, thousands of ESRD patients can unite, share their stories, and lean on each other. In doing so, they often find strength they didn't know they had, and that's a beautiful thing.

Sincerely,

Merida Bourjolly,
President of DPC Education Center Board of Directors

CEO's Message



I hope you enjoy the latest issue of *The Kidney Citizen*. Recently, DPC celebrated our 20th anniversary, and we are immensely proud of the strides we have made together. Our journey has been marked by significant growth as well as a critical impact in advancing public policies to improve the lives of kidney patients across the nation.

DPC is more than an advocacy organization; it is a community. We unite kidney patients from all walks of life, providing a network of support during times of hardship and loneliness. It is well-documented that dialysis patients thrive when they bond with others facing similar challenges. At DPC, we create spaces where these vital connections can take place.

DPC is more than an advocacy organization; it is a community. We unite kidney patients from all walks of life, providing a network of support during times of hardship and loneliness.

We often focus on expanding access to quality dialysis care, but we also understand the critical importance of addressing the emotional needs of dialysis patients. Loneliness and isolation are detrimental to health outcomes, yet social stigma around terms like "mental health" persists, often associated with weakness and inadequacy. This is why communities like DPC are more crucial than ever, offering a sanctuary where dialysis patients can relate to others, make their voices heard, and witness others triumph. And it is why the DPC Education Center maintains a strong relationship with the American Psychological Association (APA).

In the end, we know how difficult a diagnosis of End Stage Renal Disease (ESRD) can be, and how dialysis patients must endure drastic change when adjusting to their "new normal." When patients contribute articles and letters to the editor, engage with others via Facebook and Instagram Live sessions, and gather in Washington, D.C. to amplify their voices, they become part of something larger than themselves. They learn that they can take control of their future.

We look forward to continuing to give dialysis patients the tools to improve their physical and emotional well-being. Thank you for being part of our community and for your continued support. Together, we will make the world a better place for kidney patients everywhere.

Sincerely,

Hrant Jamgochian, J.D., LL.M.
Chief Executive Officer, Dialysis Patient Citizens

GOALS

The Secret Ingredient for Success





By Eniola King, MPsy, PsyD Candidate,
 Institute for the Psychological Sciences and
Stacy Ogbeide, PsyD, ABPP,
 Board Certified Clinical Health
 Psychologist, UT Health San Antonio

Goals, goals, and more goals – a topic important for those living with chronic kidney disease and going through dialysis. Self-management is one of the hallmarks of having a chronic disease, yet many people living with chronic conditions do not know where to start. If you feel stuck in the management of chronic kidney disease or your options are no longer working, setting goals that are “SMART,” or specific, measurable, achievable, relevant, and time bound may be for you! There is research to support that those who write down their SMART goals have a higher likelihood of following through and sticking with their goals. So, don’t lose heart! We’d like to share a few thoughts and ideas about how to use SMART goals to improve the management of chronic kidney disease.

1. S = Specific

- a. Set a specific and detailed goal to clearly describe what you want to achieve. Remember, it’s okay for your goal to be different from someone else’s and avoid being vague when stating your goal.

2. M = Measurable

- a. Create a method to document your progress to help you identify your results and determine

how close or far you are from reaching your goal.

3. A = Achievable

- a. Choose a goal that is challenging yet still sustainable for you to achieve. The key to selecting an attainable goal is to start with mini goals that will help you reach your overall objective.

4. R = Relevant

- a. Find your “why.” Consider the purpose behind your goal. Start by asking yourself, “Why is this goal important to me?” or “What will achieving this goal help me accomplish?” By answering these questions, you will uncover your motivation to keep going, even on difficult days.

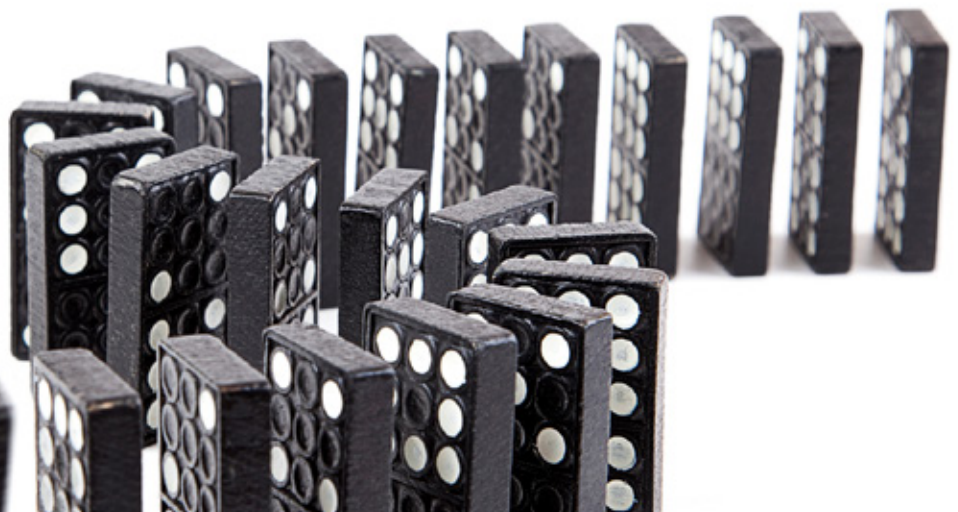
5. T = Time Bound

- a. Decide on a start and end date to meet your goal. This will help you stay organized, on track, and one step closer to success, ultimately improving your overall quality of life.

Example: SMART goal for a sodium intake dietary change

1. **Specific:** Reduce sodium to help lower my blood pressure and slow down chronic kidney disease by eating less than 1,500mg of sodium each day.
2. **Measurable:** I will track my sodium intake by using a food diary and by reading nutrition labels to identify the amount of sodium per serving for each meal.
3. **Achievable:** I will choose more foods that are lower in sodium to eat each day such as fresh fruits and vegetables, sodium-free seasonings, and stop eating fast food for one month.
4. **Relevant:** If I reduce my sodium intake it can slow down the damage to my kidneys, reduce my blood pressure, support healthy aging, and improve my overall quality of life.
5. **Time Bound:** I am going to start monitoring my sodium intake on the first day of September until the last day of the month.

Managing kidney disease and going through dialysis requires many health behavior changes. Setting clear and SMART goals can help you be successful and flourish in your life!



Resource:

Beaulieu, M., Normand, M. P., & Miltenberger, R. G. (2024). Using behavioral skills training to teach goal setting for health behaviors. *Behavioral Interventions*. <https://doi.org/10.1002/bin.2041>



By Karim Rattani,
DPC Patient Ambassador

My journey with End Stage Renal Disease (ESRD) has included much suffering, but it has also shaped me into a stronger, more loving man. Throughout all of it, I've adjusted to a "new normal" with ESRD and found that life can still be fulfilling and full of possibilities.

I worked as a chauffeur and ran a public transportation Limousine service business just before the COVID-19 pandemic began in 2020. Once the pandemic hit, most of the businesses were shutdown with an executive order and therefore I, like many others, also lost most of my customers and could no longer work. The financial stress of the pandemic proved difficult enough for me and my family.

However, during the pandemic I also experienced strange health symptoms like high blood pressure and shortness of breath with other deteriorating conditions including fatigue with loss of appetite, nausea, vomiting, and body pain. During COVID-19, these symptoms worsened and in November of 2020 I ended up in the emergency room. There, I learned that I have End Stage Renal Disease (ESRD), or kidney failure, and that I'd have to endure an arduous and frequent treatment called dialysis to survive.

I was shocked. Would I survive? Would my life ever be the same? Amid such widespread suffering during the COVID-19 pandemic, would I be able to get the care I need? I worried for my wife and my 14 years old child, who relied on me to keep the family afloat.

Finding any healthcare appointments during the pandemic, let alone appointments for surgery or dialysis treatment, proved difficult. I needed the surgery required for peritoneal dialysis (PD), or the filtering of blood through a surgical opening in the stomach, and consistent dialysis itself. That November, I began my dialysis journey, my "new normal." This was also the new way of living together for the whole family too.

Peritoneal dialysis, all things considered, has been essential for my health. It is the healthiest form of dialysis for my heart, relaxes me a bit, and has since

My New Normal



improved my mental clarity and physical strength. However, during those initial months of treatment, I lost weight and found myself vomiting often. Fortunately, I recovered and reached an equilibrium with continued treatment and improved eating habits.

Today, like every dialysis patient, I continue to experience financial and physical difficulties. But I have found that my life is still incredibly rewarding and full of potential. As I adjusted to my new normal, I gained a deeper appreciation for my family and faith.



Since I began my dialysis journey, my family and I have grown closer than ever. I have found myself lucky to have my loving wife, Munira, and my son, Kaysan, beside me. Now, I have more time to help my child with schoolwork and help my wife around the house. My family has supported me through this difficult time with grace and love. Kaysan in particular has been by my side learning with me more about life and growing into a young, compassionate, and caring human being. He was the one who encouraged me to become a DPC patient ambassador, which is why I am writing to you today and telling my story.

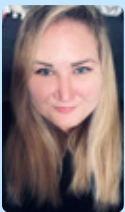
I belong to the sect of Ismaili Muslim community and because of my strong faith and spiritual education beliefs, I am a better man, father, husband, and a survivor. As I have adjusted to my new normal, I've also come to rely on God, which has strengthened me in ways otherwise impossible.

My involvement with DPC has provided me with a community of people from whom I can learn. I connect with others on the same journey in their pain and triumph. I advocate for our needs on Capitol Hill, and DPC's meaningful work encourages me to keep going as I wait for a transplant.

My "new normal" brought with it a fear of change and a fear of death. However, I discovered that while my life might not be the same as before my diagnosis, I could still live a happy and fulfilling life. With my family, faith, and DPC community, I enjoy life more every day.



Sometimes It's a Blessing in Disguise



By Layce Ryan,
DPC Patient Ambassador

I remember when I first learned about my kidney disease. I was a college student living in Kalamazoo, Michigan,

when I suddenly fell very ill. After running some tests, the doctors diagnosed me with focal segmental glomerulosclerosis (FSGS), a type of chronic kidney disease (CKD), which is the early stages of full kidney failure, also known as End Stage Renal Disease (ESRD).

In an instant, my life changed dramatically, and I was faced with the

reality that the worst was yet to come. It would be 10 years before I began dialysis at the age of 29. Despite my diagnosis, I refused to let it define me. I started a car detailing business and successfully ran it during that decade. However, contracting COVID-19 in 2020 worsened my condition, and I became a full ESRD patient, requiring dialysis.

Adapting to this “new normal” was challenging. My body had to adjust to various treatments: in-center hemodialysis, home hemodialysis, peritoneal dialysis, and back to in-center hemodialysis. This medical flux took a toll on both my body and mind, resulting in fatigue, low blood

pressure, and episodes of loss of consciousness.

Yet, I truly believe that dialysis has been a blessing in disguise. From being wheelchair-bound, I progressed to walking three miles a day and staying active. Before dialysis, I struggled with depression and mental health issues, but my mental health has significantly improved with dialysis and therapy. Although I had to close my car detailing business, I've regained my purpose as a volunteer, a kidney patient advocate, and a college student once again. With the support of scholarships from kidney foundations, I am now studying to become a therapist. None of this would have been possible without life-saving dialysis treatment.

Furthermore, my cousin plans to donate her kidney as part of an exchange program, which will expedite my transplant process. The prospect of a kidney transplant fills me with excitement for the future! Additionally, I got engaged in June and look forward to possibly becoming a mother in the future—my most cherished goal as I continue to progress.

DPC has given me the tools to adjust to my “new normal.” DPC has given me an opportunity to educate myself and to advocate for other ESRD patients, ensuring a better future for kidney patients nationwide. I am thankful to DPC for allowing me to make my voice heard and to enjoy their rich patient community.

The most important advice I can give is to thoroughly research the disease and educate yourself before starting dialysis. Use DPC's educational resources, because I wish I had known what I know now when I began my dialysis journey. Most of all, it's important to understand that patients can become better, stronger people through their dialysis journey, like I did.



Ask the Doctor



By Velma Scantlebury, MD,
DPC Education Center Health
Care Consultant

1. I have been on dialysis for three months. After treatment in the dialysis facility, I am tired and feel bloated. When will I begin to feel better?

Dialysis removes excess fluid and waste products. This happens by shifting fluid from one compartment so that the dialysis process can remove the extra fluid. This «dialysis fatigue» is experienced by about 50% of patients. Anemia, electrolyte imbalance, and stress can also be contributors to the condition.

Many recommend getting plenty of rest, eating more protein, eating a balanced diet, and exercising, which can help improve one's mood over time.

2. Why should I get a fistula or a graft? Am I not receiving adequate treatment with the catheter?

Dialysis catheters, while convenient, are generally placed for acute dialysis or long-term dialysis in patients with failed AV fistulas or grafts. The risk of complications increases with dialysis catheters compared to AV fistulas and grafts. These infections can often be life-threatening. Other complications include clotting (thrombosis) or long-term narrowing of that blood vessel, resulting in long-term obstruction or drainage of blood back to the heart from that blood vessel.

3. I have been transplanted for one year. Is it okay to switch to generic drugs instead of brand names?

Once you are stable on your transplant medications, your team can help with the decision to switch to generic drugs instead of brand names. You may need to

get frequent blood work to monitor your blood levels when switching to a new generic drug. Many insurances will dictate the need to switch to generic medications. If your transplant pharmacist feels that it is imperative to stay on brand name, they will let you know.

4. I love going outside and being in the sun. Why is skin cancer common in transplant patients?

Kidney transplant patients have a higher risk of cancer compared to the general population due to the changes that occur from the anti-rejection medications. Since these medications lower your body's ability to fight off infections and cancers, transplant patients are more at risk. The most common type of cancers are skin cancers. For this reason, it is important to wear high level skin block, and be seen annually post-transplant by a skin doctor.

I Can Do Anything I Set My Mind To



By Stephanie Dixon,
DPC Patient Ambassador

When I was diagnosed with End Stage Renal Disease (ESRD) in 2001, I felt like my life was over.

Many newly diagnosed ESRD patients share this fear, but it's possible to live a full and happy life on dialysis. While ESRD requires adjusting to a "new normal," this journey provides opportunities for growth and valuable lessons.

When I was first diagnosed with ESRD in 2001, I was immediately concerned for my two children, Jason and Joy. As the year passed, my body shut down, and I could no longer walk. Finally, I decided to have peritoneal access surgery and began dialysis in 2002.

My life improved immediately. My mind cleared as the toxins left my bloodstream. I began educating myself about my condition and how to live well on dialysis, which involved changing my diet and lifestyle. As many dialysis patients know, the diet and fluid restrictions can be difficult, but I adjusted and I'm able to stick to it to this day. Besides minor thyroid and hernia issues, I've been relatively healthy. I'm very grateful for that.

That's not to say that there have been no obstacles. For instance, I had to stop working when I began dialysis, which affected my family financially. However, I had support and worked hard to overcome that challenge. A silver lining of my situation is that it allowed me to homeschool my son and tutor my daughter, who thrived academically and received college scholarships. Joy, now 38, is a nurse practitioner in the transplant ward, and I'm incredibly proud of her. We survived, and we're doing well.



While I also recently lost my Medicaid coverage when I moved from New York to New Jersey a few months ago, I am close to overcoming that obstacle too. Through DPC, I visited my congressman's office and he promised to help. My case is being processed because of the special attention of my congressman. I'm grateful to be a part of DPC, which has given me the strength and opportunity to advocate for my health and the health of others like me.

Part of adjusting to my new normal has included discovering what it means to be a DPC patient ambassador. I'm working to change policy issues that affect dialysis patients like me, and it's been deeply meaningful. This is my first year as a DPC patient ambassador, and interacting with lawmakers has been very helpful in elevating patient voices.

We have a long way to go, but together, we can make our voices heard to change public policy and ensure patients have access to the care they need and deserve.

All in all, I learned one lesson over the course of my dialysis journey: I can do anything I set my mind to. Adjusting to my new normal demonstrated to myself and others that I have the strength to overcome virtually every challenge from ESRD. I couldn't do it alone: DPC has proven invaluable to my success. I hope other patients read my message and rest assured that they too can successfully adjust to their new normal.

Kidney-Friendly

Recipes



Thanks to **Fanny Sung Whelan, MS, RDN, LDN**, a member of the **Ed Center Advisory Council** and a registered dietitian who works with people with all stages of kidney disease, for providing us with two great kidney-friendly recipes* to kick off summer! These recipes were submitted by patients to Dialysis Clinic, Inc. (DCI) for inclusion in their Kidney Cooking cookbooks.

**Always check with your nutritionist before incorporating new foods or recipes into your diet to make it is right for you.*



Shrimp Scampi

This recipe was submitted by Ashley Sellers for the **DCI Kidney Cookbook**

Ingredients

Makes 4 Servings

- ¼ c. all-purpose flour
- ½ tsp. ground black pepper
- 1 tsp. crushed red pepper
- 1 lb. shrimp, peeled and deveined
- 4 T. canola oil
- 2 cloves garlic, minced
- 2 T. white wine
- ¼ c. lemon juice
- 2 T. butter, cold, cubed
- 1 T. parsley, chopped

Instructions

In a large bowl, combine the flour, black pepper, and red pepper flakes. Toss the shrimp in flour mixture and coat evenly. In a large, non-stick pan over

medium-high heat, heat half of the canola oil. Sauté the shrimp for approximately 3 minutes on each side or until pink and cooked through. Transfer the cooked shrimp to a plate or sheet tray to rest. In the same pan, combine the garlic, wine (or chicken broth), and lemon juice. Using a wooden spoon, stir the mixture and cook until it simmers. Turn off heat and stir in the cold butter in small amounts until it is all in. Add the shrimp back to the pan. Add parsley and toss or stir until shrimp is coated.

Notes: Low sodium chicken broth may be substituted for white wine.

Nutrition Facts (Per Serving)

- Calories: 230
- Sodium: 196 mg
- Potassium: 166 mg
- Phosphorus: 220 mg
- Protein: 27 g



Zucchini Cake

This recipe was submitted by Frances Graves for the **DCI Kidney Cookbook**

Prep time: 20 min
Cook time: 1 hour
Total time: 1 hour 20 min

Ingredients

Makes 24 servings

- 4 eggs
- 1½ c. vegetable oil
- ½ c. brown sugar
- ½ c. white sugar
- 2 T. molasses
- 3 c. grated (raw) zucchini
- 3 c. flour
- 1 tsp. baking soda
- 1 tsp. baking powder
- 1 tsp. cinnamon
- ¼ c. chopped nuts (optional)

Instructions

Beat eggs. Add vegetable oil, sugars, and molasses and zucchini. Mix until blended. Combine flour, baking soda, baking powder, cinnamon, and add to first mixture. Blend in nuts, if using. Bake in a greased and floured 9 x 13 inch pan for 1 hour at 350°F.

Nutrition Facts (Per Serving)

- Calories: 239
- Potassium: 102 mg
- Sodium: 68 mg
- Phosphorus: 47 mg
- Protein: 3 g



DPC's 2024 Advocacy Day and 20th Anniversary Celebration



By Megan Hashbarger,
DPC Vice President of
Government Relations

This past May, DPC hosted our annual Advocacy Day in Washington, D.C., where we brought together patients, family members, and care givers to meet with their Members of Congress to elevate the patient story for dialysis patients. This year, we had 65 advocates attend, representing 25 states, who had almost 80 Congressional meetings.

Our patients spoke to Congressional offices asking them to support H.R. 6860 – The Restore Protections for Dialysis Patients Act and H.R. 5027/S. 4469 – The Chronic Kidney Disease Improvement in Research and Treatment Act. These two bills would improve



access to quality health care coverage as well as innovative treatment for patients.

Specifically, H.R. 6860 – The Restore Protections for Dialysis Patients Act, would restore the longstanding ability for an ESRD patient to stay on private insurance for 30 months after diagnosis.

This is important because it allows patients to continue to cover dependents, have better access to transplant, and help with the 20% cost of care that Medicare does not cover. Dialysis patients didn't choose this disease, but they should have a choice in what insurance works best for them.

H.R. 5027/S. 4469 – The Chronic Kidney Disease Improvement in Research and Treatment Act supports efforts to prevent and better understand chronic kidney disease (CKD) by ensuring appropriate reimbursement for quality care and improve patient access to the best drugs, technology, and innovations along the kidney care continuum. The bill also includes a provision which would ensure all ESRD patients have the option to purchase a Medigap supplemental plan no matter what their age is.

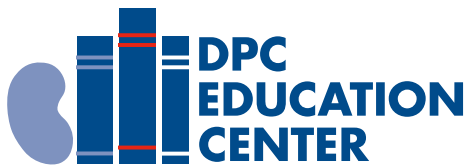
This year, we also celebrated our 20th anniversary and we were so thankful to share this occasion with our members and advocates. We look forward to our next Advocacy Day which will be in the summer of 2025.



For more information, visit:
<https://kidneyaction.org/esrd/>

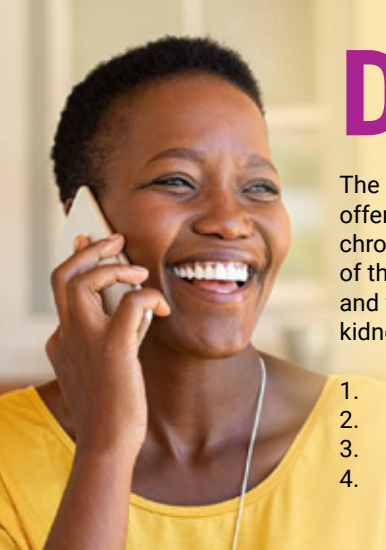






1001 Connecticut Avenue, NW,
Suite 1230
Washington DC, 20036

NON PROFIT ORG
US POSTAGE
PAID
SEATTLE, WA
PERMIT NO 2389



DPC Kidney Chat

*Connecting by phone
with other kidney patients
and their families*

The DPC Kidney Chat is a unique program that offers real time support, hope, and education to chronic kidney disease (CKD) patients at all stages of the illness, as well as support for their family and friends. It can be helpful for those adjusting to kidney disease to:

1. Have someone to listen to them
2. Gain confidence in living with kidney disease
3. Feel more in control of their life
4. Provide fellowship and community for those on home dialysis

5. Gain tips and encouragement from both someone who has personal experience and from a healthcare professional.

This program is a telephone group experience with two facilitators: a person living with CKD and a healthcare professional. The program is open to any person living with kidney disease and their family members who have a telephone. It provides a safe place to discuss aspects of living with kidney disease. The group meets on the second Tuesday of the month at 2:00 pm Eastern for one hour.



Join the call: Dial: 866-230-9002

Enter Meeting Code: 420 835 078#

Learn more and RSVP at www.dpcedcenter.org



Board Members and Advisory Council

Board Members: Merida Bourjolly, *President*; Steve Ahern, *Treasurer*; Quiana Bishop, Gene Blankenship, Andrew Conkling, Adam Goldstein, Shekeila Harris, Adrian Miller, Maria Robinson, Cheri Rodriguez Jones, Natalie Zuniga

Advisory Council: Kathryn Aebel-Groesch, *LCSW*; Sandra Amara, *MD, MHS*; Akhtar Ashfaq, *MD*; Helen Chang-DeGuzman, *MD*; Debbie Cote, *MSN, RN, CNN, NE-BC*; Steve Curtiss, *MD, FACS*; Shaminder Gupta, *MD, FACP*; Elizabeth Jones, *MSW, LCSW*; Claudine Jurkovitz, *MD, MPH*; David L. Mahoney, *MD, FASN, FASDIN*; Rajnish Mehrotra, *MD*; Stacy Ogbeide, *PsyD, MS, ABPP*; Jessianna Saville, *MS, RDN, CSR, LD, CLT*; Joanne Smith, *RN*; Fanny Sung Whelan, *MS, RDN, LDN*; Joan Thomas, *MPA, CEM, ABCP, MEP*; Steve Wilson, *MS, CSP*

