

Kidney Konnections

A publication of the



Bay Area Association of
Kidney Patients

The Bay Area Association of Kidney Patients is an all-volunteer, non-profit, 501(c)3 organization formed to educate and support Bay Area kidney patients. Visit us at

www.baakp.org

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The Implantable BIO ARTIFICIAL Kidney Research Program at UCSF by Ben Lee

On January 26, Shuvo Roy, Ph.D., Professor and the Director of Biomedical Microdevices Laboratory at UCSF, presented the latest news in efforts to develop a working miniature implantable artificial kidney. Dr. Roy's presentation was highly technical but clearly understandable to the packed audience of kidney patients and their supporters. While much work remains to be done, and the research is a few years away from clinical trials, progress is being made on this promising alternative to dialysis.

The goal, as Dr. Roy explained in the introduction, is to create an implantable bio artificial kidney as a viable renal replacement therapy. It is called "bio-artificial" because it would be a device that has both a mechanical engineered part, and also a portion that is composed of living cells. Combined, these two parts would provide the two major functions of a real kidney: first, acting as a filter to remove the body's wastes, and secondly, adjusting the hormones that help control the body's major metabolic functions (maintaining blood pressure and the calcium/phosphate balance for bone health.)

To be more specific, this device is intended to be implanted inside the patient's body. It would be about the size of a fist, small enough to fit inside a patient's abdominal cavity, similar to how a transplanted kidney is placed. There would be no

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Dr. Shuvo Roy

The Affordable Care Act (Obamacare) and the Impact on Kidney Patients by Ben Lee

The second speaker for our January 26th Educational Presentation was **Marcelo Espiritu**, Product Analyst for the Health Insurance Counseling & Advocacy Program (HICAP) at Sourcewise, an organization previously known as the Council on Aging Silicon Valley. Sourcewise is a non-profit community service agency in the Santa Clara Valley that provides expertise, education, and quality support services to seniors, their families, and caregivers. They offer many resources for seniors, but their Health Insurance Counseling & Advocacy Program (**HICAP**) to assist Medicare patients is well known. Marcelo provided an overview to the BAAKP on the Affordable Care Act (ACA) -- often referred to as "Obamacare" -- and how this may affect kidney patients.



Marcelo Espiritu

First, Marcelo gave an overview of the health insurance landscape for people with chronic kidney disease, prior to the passage of the ACA. In the United States, most insurance coverage was obtained via employer group

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SAVE THE DATE!
September 26-28, 2014
Viva Las Vegas...
For kidney patients that is!



Registration opens in April 2014 for the American Association of Kidney Patients' National Patient Meeting and Convention

The American Association of Kidney Patients (AAKP) is "Celebrating 45 Years of Progress in Patient Education and Advocacy". AAKP is the national voluntary patient organization, which for 45 years, has been dedicated to improving the quality of life for kidney patients through education, advocacy and the fostering of patient communities.

To properly celebrate this birthday milestone, the event will be held in exciting Las Vegas, NV at the **Flamingo Hotel & Casino, Sept. 26 - 28, 2014**
Special airfare and hotel room discounts are available

AAKP was founded in 1969 by a group of six kidney patients. AAKP Membership is FREE for patients and supporters; you can become a member at www.aakp.org. Encourage your doctors, nurses and other renal professionals to become members too!

The AAKP National Patient Meeting brings together patients, health care professionals, academic experts and friends of the kidney community for education and camaraderie. Attendees walk away from this event armed with the knowledge to be active members of their health care team.



Kidney patients and their supporters deserve to have fun!

For more information about the Las Vegas Convention, go to

<https://www.aakp.org/community/programs-events/> or call 1-800-749-2257

From High Blood Pressure to Denial to a Transplant

“True Confessions” — Kidney Style

This is a story about Phil Wyche, a 63-year-old longtime participant of the Bay Area Association of Kidney Patients (BAAKP) and a member of the Board of Directors since 2008. Phil was notified in 1998 that he had high blood pressure (HBP), and he knew that HBP was common in his family so he knew it was not a good situation. He admits he wasn't a good or cooperative patient then, and ignored the doctor's advice and took his blood pressure medicine infrequently. In 1999, his GP sent Phil to a Kaiser Nephrologist because his creatinine was rising. Phil admits he remained very “stubborn”, felt he was in good shape, and was not careful about taking his medications on a regular basis. He also did not want to make time for doctors' appointments and even medication.

Phil's Nephrologist, Dr. Feldman, encouraged Phil in 2001 to start looking for a kidney transplant donor from his family. (Advice, which was again ignored.) Phil didn't want to discontinue working, or participating in his favorite sports, basketball and softball. Moreover, with many years of working in a pharmacy and witnessing patients who came in year after year with kidney disease, and watching their bodies decline, Phil didn't want that happen to him. For 7 years, Phil continued to deny by thought and action that his own kidneys would fail.

Eventually, Dr. Feldman and his assistant (Sharon Windust) told him to look into the [transplant program at UCSF](#).



Phil Wyche

Phil took the class, and only then did he begin to realize the seriousness of his condition. In 2004, he was accepted into the transplant program at UCSF. Now his body and his kidneys finally had his attention!

Later, in 2008, during a softball game, he realized he was bone tired, felt horrible and had no strength. He went to his nephrologist Dr. Feldman and from that visit learned that he had to go on dialysis “right away”. Within hours, a perm catheter was inserted in the chest area and Phil started Hemodialysis at Satellite Healthcare in Redwood City within days. Later, Phil had a “[fistula](#)” inserted into his arm; upon healing (several weeks), the perm catheter was removed.

Two years after starting hemodialysis, he hurt his back while working in the yard. The doctor sent him to physical therapy and prescribed a transdermal patch with pain medication. Phil didn't like the way the medication affected him and, despite his knowledge of the [damage that NSAIDs \(Non-Steroidal Anti-Inflammatory Drugs\) could cause to kidneys](#), took Aleve, because it was the only thing that would relieve the pain. (NSAIDs are not recommended for a kidney patient!)

After 3 years, Phil was becoming very fatigued on hemodialysis and the 3 days a week schedule took time away from family & his job. He transitioned to a different form of dialysis, known as peritoneal dialysis, a variation called [Continuous Ambulatory Peritoneal Dialysis \(CAPD\)](#) with changes 5 times

(Continued on page 6)

Thank You to Our Speakers & Sponsors For our Jan. 26, 2014 Presentation!

Our Sponsor:



Our Speakers:

Shuvo Roy, PhD., University of California, San Francisco

(415) 514-9666, Shuvo.Roy@ucsf.edu

Marcelo Espiritu., Sourcewise, (408) 350-3254

And a special thanks to the
The Palo Alto Medical Foundation for use of
their facilities.

Dr. Ole Dierks is welcomed as a member of the BAAKP Advisory Board



Recently, Ole Dierks, M.D., came aboard as our second Medical Advisor, joining Toby Gottheiner, M.D., who helped create the Bay Area Association of Kidney Patients in 2007.

Dr. Dierks is assisting the BAAKP in serving the East Bay and also provides a meeting site for the East Bay Support Group, which meets once a

month at Alta Bates Summit Medical Center in Oakland. Dr. Dierks practices out of the multi-office Chabot Nephrology Medical Group and is Nephrology Chief at Alta Bates Summit Medical Center. Thank you Dr. Dierks!

external power source or external machine, so the patient would be free to be mobile. If successful, this would be a fabulous substitute for the dreary daily to three-times-a-week dialysis routine.

Best of all, if the engineering and design is successful, there would be no need for the patient to take anti-rejection medications.

How it would work

This device would work in two stages. The first stage would be a miniaturized filter, and the second stage would be a "bio-reactor." The filter stage would be a filtering system build using the modern fabrication procedure used in Silicon Valley semiconductor manufacturing. The second "bio-reactor" stage would be comprised of actual living kidney cells, grown using either donor-expanded cells, stem cell technology, or possibly even the patient's own cells. These living kidney cells would re-absorb the blood that had been filtered clean from the first stage, and would create and add those valuable hormones produced by the normal kidney.

This is a critical benefit of a bio-artificial kidney. While dialysis may help patients stay alive by partially removing toxins from the body using traditional fiber-based filters, it does not restore the patients' hormonal balance. Over time, the residual toxin build-up and metabolic imbalance are real threats to the long-term health of the dialysis patient. If successful, the bio-reactor stage of this implantable artificial kidney could greatly benefit the patient's health over the long term.

Furthermore, another goal of this design is to use "cell encapsulation" -- a technique used to isolate the living kidney tissue such that it can be receive nutrients from the body, but be "walled off" from the body's immune system. If this is successful, patients will not have to take anti-rejection medication

Where we are

Utilizing the same techniques used for making extremely tiny circuitry on computer chips, tiny holes, the same sizes as the natural holes in real kidney cell filters, can be made in silicon. This technology produces silicon nanopore membranes, and these require very little energy. The energy requirements are so small, that patients' own blood pressure will make the filter work-- so no pumps or batteries are required. The membranes can be stacked, so that the entire mechanical part of the bio artificial kidney is about the size of a deck of cards.

Animal studies have already been conducted on a small scale. After 7 days of device implantation, there were no changes in hemoglobin, and no clogging of membranes. There was fluid output consistent with normal urine. There was less than 0.1% loss of albumin, or protein, so virtually no proteins are being lost in the urine.

The next major area of research is the "bio" part of the bio-reactor equation. After the blood is filtered, fluids and salts can be reabsorbed by the living tissue, and hormonal metabolic control re-established. This requires growing kidney cells,

which can be hard. Work is proceeding now in laboratory setting to determine if we can grow kidney cells in a lab bio-reactor. These cells could come from many sources; these could be donated cells, or even the patient's own kidney cells, if they can be cultured from the patient's own healthy cells before kidney disease has progressed too far.

The living cells, if isolated into the layers of the silicon filters, could be isolated from the body's immune system. The holes in the filters designed to filter out toxins are too small for the body's own immune system cells to get through, so the kidney cells are protected from attack, and no anti-rejection medications are needed.

The experiments are in progress. Currently, cell barriers survival times are over two months, so they are promising. The target rate is over six months -- this allows a reasonable amount of time between the procedures that are needed to replenish the cell materials.

Next Steps

Much progress is expected to take place over the next two to three years. The FDA has fast-tracked this research, and this team is collaborating with the FDA so that any obstacles to approval for human use can be directly resolved, which would speed up FDA approval process. Hopefully, the goal is to start human trials in those two to three years, depending how successful the current development work is going and how much funding is available.

This raises the question, who should be participating in the clinical trials? The latest thinking is that it should be patients who are on transplant list, particularly people with high PRA (antibody) scores, which makes it harder for them to get a transplant. An implantable device that restores health using the living kidney cells bioreactor can help these patients the most, especially since these high PRA antibody patients may have the longest wait for a transplant. Also, if during the clinical trial, for whatever reason the device had to be taken out, the patient would already be on transplant list and would not have lost any accumulated waiting time.

In short, this was a fascinating and very promising presentation on cutting edge technology that could greatly benefit kidney patients, particularly those who may find this a suitable alternative to dialysis. We look forward to future progress reports! Thank you Dr. Roy for your generous donation of your time. □

Contact Information:



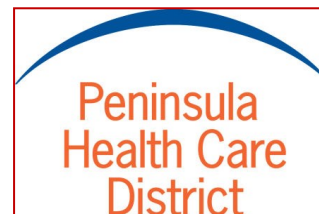
Shuvo Roy, Ph D
University of California, San Francisco
School of Pharmacy
(415) 514-9666, Shuvo.Roy@ucsf.edu

Report to the Membership on the Fall 2013 Fundraising Campaign

Founded in 2007, the Bay Area Association of Kidney Patients (BAAKP) embraces the mission to Educate and Support Bay Area Kidney Patients. Membership is open to all and our events are FREE. BAAKP is a project of Inquiring Systems Inc., a 501 (c) 3 non-profit organization. All of the funding for BAAKP comes from individual donations, corporate donations, grants, and bequests.

The all-volunteer working Board of Directors consists of kidney patients, their supporters and allied health professionals. All donations to BAAKP stay in the Bay Area; none are sent to a national headquarters. BAAKP does not have an Executive Director and nor are there office rents. We are most fortunate to have free meeting rooms, thanks to PAMF and Alta Bates Summit Medical Center.

This four-month campaign, our first since 2010, was supported, each month, by our generous community matching sponsors:



Thank you matching donors for stepping up to lead us to victory!

And kudos to all our donors who helped BAAKP reach the four month goal of \$26,400 at 9 pm on New Year's Eve!

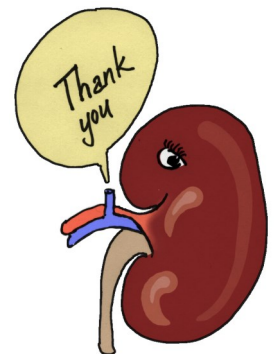
You Spoke...They Listened! Medicare delays plan to limit drug choice

At the end of February 2014, BAAKP sent an urgent email request to the membership about proposed changes to the Medicare Part D prescription insurance program (available to those over 65 **and** qualified kidney patients under 65).

Medicare (CMS) was proposing various changes to the Medicare Part D, a portion of which would limit the ability of many Medicare beneficiaries to get the prescription drugs prescribed by their doctors. This proposal would have eliminated the “protected class” status for 6 classes of drugs including **immunosuppressants**. Kidney transplant patients could be adversely affected if the medicine their doctor prescribed to maintain their transplant was not available.

We asked you to submit your comments about these changes and you did! With opposing “comments” from our membership and thousands of others, it was announced by Ms. Marilyn Tavenner, Medicare Agency Administrator, “...the drug coverage provision and some other proposed changes to pharmacy networks and drug plans would be shelved for now.” (Wall Street Journal, 3/22/2013)

Thanks to all the BAAKP members and others who helped with this effort. Please note we must stay vigilant, as Ms. Tavenner did say, “...**shelved for now**”.



Cartoon by Zina

(Continued "True Confession")

a day. The transition was great, Phil started feeling better and was able to spend more time with family, friends and CAPD made travel less complicated. However, because of the 5 times daily exchanges, Phil decided to retire from work until the happy day that he would finally receive a kidney transplant.

Then, in 2010, another setback occurred. Phil developed nausea, and was unable to digest any solid food, which led to diagnosis of carcinoid cancer in the lower portion of his stomach. Phil was treated surgically, and had a full recovery. However, Phil was then told, because of the cancer, he would be placed on the in-active list for transplantation and had to wait for three years before becoming "activated" again. For Phil, this was just one more roadblock of the many that had happened. He was devastated by this bad news, he felt he would never receive a transplant.

The prospect of a transplant was fading farther and farther away, and in the following year, he developed a bleeding ulcer and needed more surgery. Once again another setback.

However, in June 2012, with the encouragement of his nephrologist, the UCSF transplant team called and scheduled him for a stress test, x rays, heart test, and other tests to have current and up-dated information. Still no transplant in 2012; it had been 8 years on the wait list.

June 2013, the dialysis center gave him a routine shingles shot and Phil subsequently learned from the UCSF transplant team that because of the live virus inoculation, he would be taken off the transplant list, made inactive again for 90 days. What else could happen?

Then it really hit him-that nothing was going right and the prospect of getting a transplant became less with each passing day. The nephrologist encouraged Phil to talk to someone about this worsening depression. After talking with a professional health care worker, Phil became more organized in his thoughts and developed a renewed sense of purpose. For the first time, he began to advocate for himself. As a BAAKP Board member, he was a champion for others, but he now realized he needed to be his own champion. He realized he

had been holding himself back by not being persistent in his quest for a transplant.

For the next few months, Phil began to advocate more regularly with his contacts at UCSF, pushing for a transplant. He then received word that his Case Manager (Pre-transplant coordinator) was leaving UCSF and the prospect of any more delays was unsettling. There would be a 2 to 3 week gap before the new coordinator would be ready to go. With the prospect of more delays, Phil got on the phone again.

Within a few months, he got a call at 2 AM on Thanksgiving Day 2013 from UCSF with the positive news that they had a kidney for him. (Babies and Kidneys seem to come in the middle of the night!) Within an hour, Phil was on his way to San Francisco! His transplant took place at 3:00 in the afternoon on Thanksgiving Day, and he was home within 3 days. His early release was due to the determination of both Phil and his wife Kimberly. By the second day, he was walking around the hospital ward, and finally, he completed the 1 ½-mile loop requested by the nurses. He completed the exercise of walking up a mock staircase. Miraculously, the pain was not a factor by the third day.

It's been 5 months now since Phil had his transplant, he's lost weight, almost 40 pounds of water, and looks like a new man. Through it all, his wife Kimberly has made sacrifices with time away from her job, and family. She has been an extraordinary caretaker and Phil's biggest supporter. Now, Phil and Kimberly are spending more quality time with their children and grandchildren.

Phil is not proud of his early history with kidney disease, but is telling his story to those with high blood pressure and other medical problems which could lead to kidney disease. He hopes that others can profit from his experiences. Perhaps this story also will help someone to advocate for themselves and avoid a long and challenging medical history reminiscent of Phil's. □



Phil and his son

Other Kidney Resources– Check our website at www.baakp.org for more!

American Association of Kidney Patients AAKP

2701 N. Rocky Point Dr.
Suite 150
Tampa, Florida 33607
(800) 749-2257

www.aakp.org

San Francisco Polycystic Kidney Foundation

1-800-PKDCURE

[www.pkdcure.org/
sanfranciscochapter](http://www.pkdcure.org/sanfranciscochapter)

sanfranciscochapter@pkdcure.org

Transplant Recipients International Organization TRIO

2nd Thursday of each month
7:30 pm. El Camino Hospital,
Conference Room G
2500 Grant Road,
Mountain View, CA
(408) 353-2169
www.bayareatrio.org

The National Kidney Foundation

131 Steuart St Ste 425
San Francisco, CA 94105
www.kidneyca.org
888-427-5653

www.kidney.org

policies, in which your employer pays for the majority of your insurance costs. If one should lose their job, the only option for coverage would be through the [COBRA](#) (initials stand for *Consolidated Omnibus Budget Reconciliation Act*) plan, since kidney patients could not purchase their own policy due to their pre-existing condition. However, COBRA plans can be prohibitively expensive since you have to pay for the entire coverage yourself, as the employer no longer pays his portion. COBRA lasts only a limited time, usually 18 months, so one would need to convert to an individual plan, which is also extremely expensive.

The main concern for CKD patients is that kidney disease is a pre-existing condition, which would disqualify a patient from being able to purchase insurance. (CKD means chronic kidney disease with a GFR --[Glomerular Filtration Rate](#)-- equal to or less than 60 mL/min.) For patients over 65 who qualified for Medicare *prior* to their diagnosis with CKD, this is not a concern, since "pre-existing conditions" are not an issue to obtain Medicare coverage. However, any patients under 65 diagnosed with CKD, and who did not have employer group coverage, would have few options outside of the limited and very expensive coverage of the California Major Risk Medical Insurance Program (MRMIP). (Unless the under-65 patient has a GFR less than 20, which means they are in "End Stage Renal Disease" (ESRD) and would qualify for Medicare coverage when they start dialysis or receive a transplant.)

In today's coverage landscape, there are essentially three features that stand out. First, the [Affordable Care Act](#) makes it illegal for insurance companies to deny coverage to any patient on the basis of a pre-existing condition, such as a CKD diagnosis. Secondly, California has created [Covered California](#), its own Health Care exchange where individuals can shop for group coverage at prices reduced by federal subsidies for those with lower incomes who qualify. Lastly, [Medi-Cal](#)--California's version of the national Medicaid program-- is expanding to include limited income adults between 19-64 years old without children (where previously Medi-Cal was exclusively for families with dependent children, elderly over 65 years old and people with disabilities.) Going forward, single individuals with low enough income can also qualify and be insured.

Covered California, the exchange insurance marketplace, has different levels of coverage (bronze, silver, and so on), has no pre-existing conditions restrictions, and offers subsidies based on a patient's Modified Adjusted Gross Income. Will these "Obamacare" plans offer coverage for dialysis and kidney transplants? Yes, although the level of coverage will depend on which level of plan is chosen by the patient. All patients are eligible to shop for plans on Covered California, with exceptions, one being patients who are already eligible

for Medicare. If a patient qualifies for free Medicare Part A, then Covered California is not an available option to purchase insurance.

When one is on Medicare, a key consideration is how to deal with out-of-pocket costs. Medicare generally covers 80% of medical costs, and the patient has to cover the remaining 20%. Typically, the patient has to enroll in some sort of secondary plan. Medicare would then "coordinate" with these other plans to work out how the costs would be split between them.

Typical options for this secondary coverage are employer group plans, and also plans offered by most insurers called "MediGap" plans. Medigap enrollment rules were not changed by the Affordable Care Act. While insurers can no longer deny coverage on the basis of pre-existing conditions, that restriction does not apply to MediGap plans. So unfortunately, in California, an ESRD patient under 65 can still be denied coverage when trying to buy a MediGap plan. As an alternative, [MRMIP](#) is still funded by the State of California through this year for those with pre-existing conditions, so that can still be used as secondary coverage.

For those people turning 65, there is an open enrolment period of 6 months after the date when you qualify for Medicare, where you can sign up for MediGap coverage without a health screening. This is another way to sign up for secondary coverage without worrying about any pre-existing conditions.

The issues surrounding health care coverage for kidney patients can be very complex, as each patient's situation is different, and Medicare, insurance coverage, and the law can interact in complex ways. Overall, the biggest advantage offered by the Affordable Care Act is that people with chronic diseases can no longer be denied coverage for the plans purchased via Covered California. Because of the complexity of the issues, patients are encouraged to visit www.mysourcewise.com.

Thank you Marcelo for your time! □



Contact Information:

Marcelo Espiritu

HICAP representative

Sourcewise, www.mysourcewise.com

(408) 350-3254

This newsletter is not intended to take the place of personal medical advice, which should be obtained directly from your Doctor.



Post Office Box 2332
Menlo Park, CA 94026-2332

Phone: (650) 323-2225
Email: info@baakp.org



Please visit our website at
www.baakp.org
to make a donation, see back
issues of
our newsletters, and view
videos of our past meetings.
Your help is greatly
appreciated!

Educating and Supporting Bay Area Kidney Patients !

SAVE THESE DATES !

Palo Alto Medical Foundation, 3th floor
795 El Camino Real, Palo Alto, CA

Educational Events (1-4 pm)

- **May 18, 2014**
- **September 21, 2014**

Support Group Meetings (1-3 pm)

- **April 27, 2014**
- **June 22, 2014**
- **July 20, 2014**

East Bay Support Meeting (1-3pm)

Alta Bates Summit Medical Center
400 Hawthorne Ave., Oakland, CA
(BART station: MacArthur)

- **April 6, 2014**
- **May 4, 2014**
- **June 8 2014**

Board of Directors' Meetings

**1st Tuesday of the month
At 6:00 pm**

*If you would like to join us in any of the many activities necessary to run this group, please contact us.
info@baakp.org (650) 323-2225*

May 18, 2014 - Chronic Kidney Disease: Staying One Step Ahead, An Update

The BAAKP is proud to introduce the **Charles & Joan Horngren Kidney Education Series**. Through the generosity of the Horngren Family we introduce this unique series, with special speakers and festivities.

On May 18, 2014, the Bay Area Association of Kidney Patients will feature our very own medical advisor and Palo Alto Medical Foundation Nephrologist **Toby Gottheiner, M.D.** His topic will be **Chronic Kidney Disease: Staying One Step Ahead, An Update**.

This is a comprehensive presentation that is suitable for patients and caregivers dealing with all stages of kidney disease. It will address the following important topics: stages and complications of CKD, strategies to delay progression, preparation for Dialysis & Transplant and new guidelines for kidney disease. We will also feature our ever-popular **Patient Panel**.



Dr. Gottheiner

Don't miss this **FREE** event on **Sunday, May 18, 2014**, from 1 to 4 pm at the Palo Alto Medical Foundation, 795 El Camino Real, Palo Alto, CA 94301. Refreshments will be served! Door Prizes Too! **To reserve your seat, please go to the website at www.baakp.org or call 650-323-2225.**

The Charles & Joan Horngren Kidney Education Series