This is a Good Time to Be a Kidney Patient! by Christie Chapman

On January 24, 2015, the Bay Area Association of Kidney Patients held its first Educational Presentation in the East Bay, with about 100 attending. We welcomed Dr. Ole Dierks, nephrologist with Chabot Nephrology Medical Group, to our 25th Educational Presentation. Dr. Dierks, also a Board of Directors
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Bay Area Association of Kidney Patients

Everything You Ever Wanted to Know About Your Dialysis Access by Christie Chapman

Our second presenter for the January 2015 Educational Presentation was Dr. John Bry, a vascular surgeon with Bay Area Surgical Specialists. As a vascular surgeon for 20 years, he has narrowed his focus to dialysis accesses, which now makes up about 90% of his work. Dr. Bry discussed “Dialysis Access: Your Prized Possession, Our Shared Responsibility.”

There are now over 600,000 ESRD (End Stage Renal Disease) patients in the U.S., chiefly because of increasing rates of diabetes, high blood pressure, and longer lifespans. The numbers of kidney transplants are now over 17,000 per year but are not keeping up with the increasing numbers of new ESRD patients. Only about 8% of dialysis patients opt for peritoneal dialysis; the rest are on hemodialysis. There is a delicate balance vascular

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surgery must maintain when creating a vascular access for hemodialysis. The access must be able to handle the increased blood flow that dialysis requires to remove toxins from the blood and remove fluid buildup while, not overwhelming the heart.

Dr. Bry began with the history of the vascular access in dialysis by the pioneers of vascular surgery. In 1896, Jaboulay and Briau were the first to describe the successful results of suturing cut ends of arteries in an end-to-end configuration. This technique helped prevent the blood from clotting, (thrombosis). In 1912, Alexis Carrel was awarded a Nobel Prize for perfecting this technique with the use of pexing, or traction sutures, which aligned the vessel ends and created evasion of the walls. In 1924, Georg Haas performed the hemodialysis on the first patient; clotting was a problem until Heparin was introduced in 1927. In 1943, Willem Kolff created an artificial kidney made with wooden drums, laundry tubs, and cellophane tubing (the rotating drum kidney), using glass tubes connecting an artery and a vein in the leg. In 1949, Allwall began development of a dialysis system, which conducted blood through rubber and glass tubing. In 1960, Belding Scribner improved upon this system with a device, worn externally, but connected internally to the radial artery and cephalic vein. This device was called the Scribner shunt. Scribner established the first outpatient dialysis center in Seattle that accommodated 9 patients and expanded in 1964 to 47 patients dialyzed twice per week. James Cimino noticed how penetrating arm injuries caused abnormal connections between the artery and vein. He introduced fistulas to dialysis in 1966. In 1977, Graez followed with the introduction of the brachiocephalic fistula; and Barnett in 1979 with the brachiobasilic fistula.

Dr. Bry explained how an arteriovenous (AV) fistula is created by connecting a surface arm vein to an artery and described the three (3) locations in the arm where a fistula can be placed; one in the forearm and two in the upper arm. The placement of the fistula determines how the arteries and veins will be connected and how complicated the procedure may be. The Cimino and brachioce- phalic fistulas can be completed with local anesthetic, but the basilic transposition requires regional or general anesthetic, so the basilic transposition is not the first choice for a fistula. After placement, the fistula must mature 6-8 weeks before it is usable for dialysis.

Because there was a high incidence of failure of both the Schribner shunt and a variety of external catheters, and patients with poor veins could not have a fistula created, synthetic and biological grafts for dialysis were developed. In 1972, Dunn developed a knitted Dacron textile tube graft, which was connected to an artery at one end and to a vein at the other. The same year, Chinitz reported on the successful use of a carotid artery secured from a cow and prepared for human implantation and Soyer reported on a flexible tube graft made of Teflon plastic. In 1976, Baker reported the first study of patients successfully treated with the Teflon graft. In 2001, Lipkowitz developed the preparation of human cadaver vessels for implantation as dialysis grafts. They are called Cryoveins and arteries. Dr. Bry described and provided illustrations for a variety of techniques for creating grafts, which can be placed in various locations in the body, such as the arm, neck, thigh, or chest. Vascular surgeons have many options for using grafts and fistulas for dialysis accesses these choices are limited only by the creativity and skills of the surgeon.

Catheters can also be used for dialysis. (A catheter is a soft tube that is placed in a large vein, usually in your neck.) It is meant only as a temporary access allowing immediate dialysis, and is usually placed under emergency circumstances. However, it is the least desirable approach to dialysis with significant risks of infection and clotting.

Fistulas have many benefits over catheters and grafts. There is lower infection risk, and only mild anesthesia is needed. Steal (shortage of blood in hand that can cause pain, coldness, discoloration, and ulceration) risk is lower. Patency (remains open or unobstructed) lasts for 2-8 years, as opposed to 9-18 months with grafts. Healthcare costs are lower. Grafts, however, can be used in 1-10 days post surgery, while fistulas must mature over 6-12 weeks. His presentation included many photographs of various types of fistulas and even showed a photo of the surgery itself. Please see our video, available online at www.baakp.org.

Dr. Bry shared ultrasound photos demonstrating good and poor fistula blood flow. Ultrasound monitoring helps to evaluate the presence or absence of turbulence within the fistula. If flow is smooth and non-turbulent, the
access is unobstructed. With gray scale imaging, the diameter of the access can be measured. The anastomosis (connection) between the artery and dialysis access can also be measured using ultrasound.

Dr. Bry emphasized the importance of having a good vascular access. He said, “Your life can depend on it!” A fistula is the preferred vascular access, while a catheter is least preferred. When dialyzing with a catheter instead of a fistula, there is a 38% increase in cardiac events, 100% increase in fatal infections and 50% increase in mortality from all causes. In 2003, the Centers for Medicare and Medicaid established the Fistula First Initiative because functioning fistulas were recognized as superior to catheters and grafts.

Also important to your dialysis access maintenance are cannulation (needle insertion) techniques. He emphasized avoiding multiple needle sticks to a small (½ to 1 inch) area of the fistula, causing blood vessel narrowing due to scar formation, or weakening of the fistula wall, predisposing that area to dilation, aneurysm formation, and rupture. The rope ladder technique favors gradual enlargement and maturation along the entire length of the fistula and minimizes these risks. The buttonhole technique can limit the process of dilation because the fistula is accessed in two (2) isolated locations. In a study comparing Buttonhole to Rope ladder, there was no reduction in pain or in the survival of the vascular access. There was a higher risk of local and systemic infection and accumulation of hyperplasia (scar tissue) at the buttonhole.

Dr. Bry closed by addressing patient concerns such as fistula outflow obstruction and aneurysms (enlargements of a blood vessel). He provided images and explanations of corrective procedures taken to address these issues and save the fistula, or remove aneurysms and unsightly scars. Finally, we learned that Dr. Bry emphasizes transplant over dialysis, stating, “On a more positive note and with an eye to encouraging patients to join a transplant waiting list, studies have shown that the survival rate of patients with a transplant is improved by 80% compared to those who remain on dialysis.” Thank you Dr. Bry for your wonderful presentation!

Contact Dr. John Bry at Bay Area Surgical Specialists, 925-932-6330, http://www.bayareasurgical.com/

Free Kidney Education Classes Offered by Dialysis Provider

Free 90-minute Kidney Smart Classes are offered to kidney patients and their supporters. They cover:
- kidney functions
- causes of chronic kidney disease (CKD)
- medications, diet and nutrition
- treatment options

For more information and to find classes near you please visit www.kidneysmart.org or call 1-855-343-4951 to register.

Thanks, Mila Kelman, former BAAKP Board member, for alerting us to this opportunity! Mila, an educator with DaVita in Redwood City, can be reached at 650-365-0129.

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

Living Donor Advocacy Coalition Needs Your Support!

A new organization, called Waitlist Zero (http://waitlistzero.org/) is seeking your support for changes which would increase the number of kidneys available for transplant to the over 100,000 patients currently waiting.

For its first campaign, Waitlist Zero is working to persuade a policy change at the Division of Transplantation of the Health Resources and Services Administration (HRSA). Currently, most HRSA funds are promoting deceased donation. However, statistics show that the current kidney shortage will not be solved by deceased donation alone.

BAAKP knows that living donation is safe for the donor and that those transplanted kidneys have longer lifespans than deceased donor kidneys.

Go to the Waitlist Zero website, read the information and submit a letter (sample included on website) to HRSA. Encourage the policy-makers in Washington to change their thinking about (and funding for) living kidney donation! Thank you, Thomas Kelly, (who is himself a non-directed living kidney donor) for bringing this important campaign to our attention.
Department of Nephrology website. He noted that there are over 30 nephrology blogs, with 18 selected by the official blog of the American Journal of Kidney Disease (http://aikdblog.org/). These online resources provide access to Clinical Practice Guidelines and other valuable educational materials. In addition, patients have access to their own electronic medical records through patient portals, plus access through apps that can be downloaded to their phones, making their medical records portable.

The movement of evidence-based medicine goes back to the 70's and 80's with improved clinical guidelines and quality of care for patients. Kidney disease guideline development began in the 90's, when, in 1993, the first clinical practice guidelines were developed by the Renal Physicians Association, focusing on adequacy of dialysis. In 1997, Dialysis Outcome Quality Initiative (KDOQI) furthered that emphasis. In 2002, Kidney Disease Outcome Quality Initiative (KDOQI) added the management of Chronic Kidney Disease (CKD) and Acute Kidney Injury (AKI). In 2003, Kidney Disease Improving Global Outcomes (KDIGO) brought together international experts who developed guidelines based on evidence, which is graded. In 2012, KDIGO added Guidelines for Evaluation and Management of Chronic Kidney Diseases. Dr. Dierks mentioned an iPad app www.kdigo.org, which can be downloaded free from the Apple Store.

Our speaker questioned the sole use of guidelines and expressed that clinical experience cannot be ignored. Dr. Dierks emphasized the importance of a healthy perspective. Most of his patients are treated as outpatients and, less than 5% require dialysis. A large proportion of older patients without a significant degree of proteinuria (protein in their urine) have a very slow progression to kidney failure. He is encouraged by recent statistics, which show the incidence rate (new cases) of dialysis has been decreasing over the last three (3) years, along with lower mortality rates in the dialysis population.

Dr. Dierks suggested “thinking outside the allopathic box” is a good idea and supports integrating traditional Chinese medicine with Western Medicine. Patients with advanced kidney disease have many symptoms: insomnia, pain, cramping/musculoskeletal complaints, infertility, itching, nausea/vomiting, and fatigue/weakness. Physicians can treat these symptoms by giving patients medicine and increase patients’ pill burden or encourage alternative therapies, such as acupuncture. For instance, human MRI studies showed that specific parts of the brain would light up when scanned, depending upon where the acupuncture needles were placed. A large meta-analysis of 29 randomized controlled trials using acupuncture for chronic pain included over 17,000 patients and proved acupuncture group results superior to sham and non-acupuncture groups.

Dialysis has come a long way since 1962 when Dr. Belding Scribner opened the first outpatient dialysis unit in Seattle. Today, patients can choose to dialyze more frequently at home, said Dr. Dierks, with options such as home hemodialysis. “Home hemo” dialysis providers give extensive training and 24-hour support. Patients have better volume control, resulting in far less blood pressure medication. There is lower risk for post-dialysis hypotension (drop in blood pressure), and better phosphorus control, with fewer or no phosphate binders needed. Recovery time after dialysis is shorter, and energy levels are higher. There is better waste clearance with improved outcomes: patients are living longer, and are more independent. Regrettably, only 1.7% of dialysis patients are on home hemodialysis.

Organ transplant is still the gold standard for end-stage renal disease. Dr. Dierks encourages patients to seek a pre-emptive transplant (prior to dialysis), which is available when kidney function drops to 20% of normal. In all, only 20% of patients needing an organ transplant ever get one. Of the 180,000 patients on the transplant list, 90% are waiting for kidneys, with the results that the average wait time for a deceased donor kidney is 3-6 years in the Bay Area. About 50% of deceased donor transplants fail after 10 years, so a living donor is preferred. Currently, organ transplantation is only possible with medications, which suppress the immune system, resulting in many unwanted side effects: high blood pressure, diabetes, cardiovascular disease, infections, cancer, and, paradoxically, compromised kidney function.

Looking to the future, there are many advancements on the kidney transplant horizon. Dr. Dierks started by explaining the principles of CHIMERISM. In 1945, Dr. R.D. Owen observed healthy adult, non-
identical cattle twins with two different blood types in each of their immune systems. This is called chimerism. In utero, the calves’ placentas fused and blood cells traveled from one animal to the other’s immature immune system, resulting in “tolerance”. The immature immune system had learned to accept the foreign cells. In 1954, Nobel-Prize Winner, Dr. Medawar injected bone marrow cells from a non-identical mature mouse into an unborn mouse. The newly born mouse then accepted skin transplants from that adult mouse.

The challenge is to replicate what was done with an immature immune system in a mature immune system. The prerequisite is that the match of the donor and recipient is as close as possible. Recently, trials with living related and unrelated donors showed encouraging results (Stanford, Northwestern and Harvard University). In the mature immune system, physicians must reduce the recipient’s immune response at transplantation using irradiation, chemotherapy, and/or infusion of anti lymphocyte serum (conditioning). This conditioning, prior to the transplantation of, for example, bone marrow leads to the presence of a donor/host cell mixture (chimerism) and tolerance to transplanted cells.

Unlike bone marrow transplantation in the treatment of blood cancer requiring very toxic, so called “ablative conditioning”, solid organ transplantation requires less intense conditioning. This is based on findings that it is not necessary to replace the entire bone marrow with donor cells to create lasting tolerance to transplanted organs. Between 50-75% of patients can be weaned off immune suppressive medications entirely depending on donor compatibility and the protocol used. (Editor’s note: Please see the BAAKP newsletter featuring one of our member’s experiences with his transplant as a participant in a Stanford research project; he is now off of all immunosuppressants—Kidney Konnections Fall 2013.)

New technological devices include the Wearable Artificial Kidney (WAK) which weighs 10 pounds and uses light 9V batteries to power the pumps. There is limited amount of dialysate liquid needed (375 ml-about 1 ½ cups) because of continuous regeneration of dialysate. Recent U.S. research trials used catheters because European trials using venous needles had problems with the needles dislodging with movement.

Of more immediate interest is the implantable bioartificial kidney research of Dr. Shuvo Roy, which is taking place right here in the San Francisco Bay Area. This device will be placed in the patient in a fashion similar to a kidney transplant. It consists of a bioreactor portion with a small amount (1 gram, approximately 0.03 ounces) of the patient’s renal tubular cells which are seeded on membranes, mimicking kidney tubules. The second part is a mechanical filtration device. Researchers think it will take 4 to 6 more years of research, but will eventually cost less than a transplant, the patient will be able to forgo immunosuppressive drugs, and should last about 10 years. (Editor’s note: Dr. Shuvo Roy visited BAAKP in January 2014; his presentation is featured in our Spring 2014 issue of Kidney Konnections.) The implantable artificial kidney project is also described in detail in a UTube video with Dr. Shuvo Roy of UCSF.

Finally, there is 3D printing. In 2009, reproduced cells were used to treat children with a malformation of the spine leading to a non-functional bladder. Bladder cells were reproduced to grow artificial bladders, which were then implanted in the children. Years later, as an adult, one of the children was able to come off dialysis. With this 3-D printing technology, the potential to grow organs is now possible. Recently, a Japanese research group was able to grow a nephron. Each kidney is comprised of 1,000,000 nephrons and with the nephrons and the blood vessels required, an entire organ could be created.

Thank you, Dr. Dierks for this educational and optimistic look into the future of various treatments for chronic kidney disease. We look forward to further installments! ☐

Contact Dr. Ole Dierks:
Chabot Nephrology Medical Group
(510) 451-0996  http://chabotnephrology.com/
A New Beginning for Me!
A Kidney Disease First Person Story

My name is Iris Corina; I am a 65-year-old single mother of two lovely daughters, with three wonderful grandsons, and two younger sisters, all of whom supported me during a very challenging period of my life. I enjoy cooking, eating, making jewelry, and spending time with family and friends. After working for the State of California for approximately 25 years, I retired in 2003.

Less than a year ago, on June 9, 2014, my life changed, and I was given the gift of continued life. But wait, there is more to the story...

As an adult, I had High Blood Pressure, as did most of my relatives: in fact, I began blood pressure medications while still a teenager. On September 4th, 1967, I received a blood transfusion after the delivery of my oldest daughter. However, it was not until 1999, that I heard a television announcement, which warned recipients of a blood transfusion about Hepatitis C (Hep C). Shocked and frightened, I had my blood tested, and yes, I was infected. (Editors’ note: Hep C is a virus, which infects the liver.)

In the early 1990’s, my general practitioner (GP) referred me to a Nephrologist because of high blood creatinine tests. This first Nephrologist said there was some renal disease, but that no treatment was required. He said I was to drink plenty of water and keep my weight down. Drinking water was easy; keeping my weight down was a problem. I ballooned to 231 pounds by 2013. In 2013, this doctor announced I would have to go on dialysis.

I panicked and became very angry with my Nephrologist and various physicians. I trusted them to take care of me—why did they not help and direct me? I didn’t know what caused my renal failure; however, the journey to my present had begun.

So, I changed doctors and was introduced to Dr. Hussain Gilani, who advised me to lose weight and provided me with websites showing eating plans and other helpful information. He ran lab tests and helped me to decide when to begin dialysis. At Satellite WellBound in Emeryville, the nurses and staff taught me how to perform home peritoneal dialysis, as well as helping with coping mechanisms and dietary support. I was not the best patient and wanted to give up at times, but they, especially Kevonya Elzia, encouraged and supported me in a way that I will never forget. In the middle of that night, Vicki said, “We have a kidney for you.” (Question from the editors: does every kidney offer come in the middle of the night?)

Unbelievably, I would be getting a kidney that day. I had been on dialysis for five months and nine days! Later, I realized that if I had not received that Hepatitis C contaminated blood transfusion so long ago, I probably would not have received a kidney so quickly in 2014. You see, the kidney donor also had Hepatitis C, and my own infection with the same virus put me close to the top of the “list” because many recipients will decline this kidney. I would like to encourage others who have Hep C to accept such a kidney; it will change your life.

In an instant, I felt sad for the family who lost someone they loved, happy that I would receive a kidney, and then, disbelief at my good fortune. Never in my life had I felt so many emotions at one time!

It’s not all a bed of roses, and there are still trying times in my life because of the transplant, but I would not trade the journey for anything. We have to go through the rain in order to enjoy the rainbow.

My rainbow is my belief in God, my wonderful family, my loving friends, the physicians, and all of the staff at Satellite WellBound, California Pacific Medical Center and last, but not least, the BAAKP, which offers support for patients in all stages of chronic kidney disease.

I volunteer as an informal patient advocate, where I...
meet with patients, either in person or by telephone. I share my experiences prior to dialysis, during dialysis, and after kidney transplant. I’ve never met some of the people from these phone calls, but they are happy to talk with someone who understands what they are going through. I pass along the encouragement given to me by my family, friends, and the many medical professionals to help these new patients see the rainbow and let them know that there is life during and after dialysis with a transplant.

Thank you Iris, for your inspiring story!

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At the January 15, 2015 Educational Presentation, Dr. Gaurav Mathur, a physician with Summit Hospital in Oakland, described a unique way to track your medical records.

**Omni Health Timeline** is an iPhone/iPad app that helps you keep all your medical records in one place. Easily store, search and share your health information, including medical records from your doctor and information you record yourself. Designed by a doctor, Omni Health Timeline is simple and easy to use. All information is private, secure and restricted by you.

1. On your iPhone/ iPad, go to [www.omnitimeline.com](http://www.omnitimeline.com) and tap the link to download Omni Health Timeline free from the App Store.
2. Launch the app, enter your name and basic information.
3. Tap the “+” button to enter medical information. For example, if you take prescription medication, you may want to enter your dose (e.g. 5mg of Norvasc) and select “Rx” to tag (label) it as a medicine. Or you might write “Diabetes” and tap “Hx” to tag it as a health problem.

You can store any medically related information: blood sugar readings, a flu shot, medications, symptoms, and test results that you scan with the iPhone camera). You can even store and tag medical expenses and doctor contact info.

Doctors depend on a patient’s memory, but we all forget things. By entering information and scanning reports as you get them, you can provide your doctor with your clinical history. Use the app to share all or a part of your timeline with someone you trust—your doctor or a family member. Parents can track their kids’ illnesses, injuries, and milestones. Adults can manage their elderly parents’ health issues and medicines. Pregnant women can organize updates from their frequent check-ups.

Learn more at [www.omnitimeline.com](http://www.omnitimeline.com)

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

**American Association of Kidney Patients**

2701 N. Rocky Point Dr. Suite 150
Tampa, Florida 33607
(800) 749-2257
[www.aakp.org](http://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](http://www.bayareatrio.org)

**The National Kidney Foundation**

131 Steuart St Ste 425
San Francisco, CA 94105
[www.kidneyncf.org](http://www.kidneyncf.org)
888-427-5653
[www.kidney.org](http://www.kidney.org)
CKD & Transplant Strategies: Learn to Advocate for Yourself

On May 17, 2015, BAAKP will stage the next installment of the Charles & Joan Horngren Kidney Education Series. Our featured speaker will be Risa Simon, Founder and CEO of TransplantFirst Academy and The Proactive Path. Risa is a preemptive living donor kidney transplant recipient, and, after discovering patient education voids while dealing with her own health challenges, decided to devote her career to coaching kidney patients. Joining her will be the popular patient panel.

Ms. Simons will discuss “Successful Strategies for Hopeful Transplant Recipients”. You must attend if you want to:

- avoid dialysis
- end the wait for a transplant
- attract a living kidney donor
- regain control of your life

Don’t miss this FREE event on Sunday, May 17, 2015, from 1 to 4 PM at the Palo Alto Medical Foundation, 795 El Camino Real, Palo Alto, CA 94301. There will be ample time for social interaction. Kidney-friendly refreshments and door prizes too! To reserve a seat, please go to www.baakp.org or call 650-323-2225.