In February 1995, Faye Blanchard Robichaux’s cousin and dear friend, Gayle Clement, was living with kidney disease, and her health was quickly declining. Doctors told the 43-year-old woman that it was time for a transplant. “How can I help?” Faye thought. Without hesitation, she decided to give Gayle one of her kidneys. “I know she needs a new kidney. I need only one to live. If there is a match, I’ll do it.”

Tests were done on Faye and Gayle, and they were a remarkable match for cousins. Faye’s husband, John Harvey Robichaux Jr., could not understand why she would do this. Her daughters supported her decision, but her son and husband remained reluctant. But Faye knew that Gayle was too dear; she needed to live a fulfilling life—without dialysis.

Faye and Gayle drove to the hospital together while talking, reminiscing and laughing, as if they were going on a shopping trip. They had always been close. Gayle said that Faye had always been a kind, giving person; she was amazed and, of course, eternally grateful for her offer.

On May 11, 1995, at Ochsner Foundation Hospital in New Orleans, two teams of transplant surgeons performed the miracle. Within four hours, one special nurse was carrying Faye’s beautiful rich kidney to the other operating room for the other surgical team to transplant into Gayle.

Gayle’s kidney function was restored and her life color returned. Eyes were closed in prayers of thanksgiving by her family and John Harvey. Within hours after the transplant, Gayle was wheeled into Faye’s room. Their eyes met and they held hands. What can you say at a time like this? The miracle continues to this day.

Although Gayle was healthy again, this was not the end of the transplant experience for Faye and John Harvey. The rich bonds of love and sharing within the Robichaux family would once again motivate a selfless act. John Robichaux Sr., better know as “Pup” to family and friends, had been fighting kidney disease.
This issue brings you a smorgasbord of transplant topics, from how to enjoy your summer bathing suits despite your scars, getting your picky eater to eat, increasing organ donation and exercise for kids to the hepatitis B infection, drug interactions, growth hormone for kids and waiting for a transplant.

Take note of the transAction Council membership card below. I encourage you to join this free organization and receive the many benefits of membership, including a free home subscription to Transplant Chronicles. Just send this form back today and you’ll become a member...it’s that easy!

For those of you who missed transAction’s Road Show in Denver this January, you’ll be happy to know that it is moving from the Colorado Rockies to the desert of Scottsdale, Arizona, on July 24. For more program and registration information, call the NKF at (800) 622-9010 or visit our website at www.kidney.org.

Beverly Kirkpatrick for the Editorial Board

Sign Me Up...

FOR A FREE MEMBERSHIP IN THE TRANSACTION COUNCIL

to receive all of the benefits of membership: a membership card and pin; quarterly issues of TransAction Council Connection membership update and Transplant Chronicles newsletter; information on transplant athletic programs, a voice in legislative and public policy issues; participation in NKF educational programs and activities.

Just fill out the form below and mail it to the transAction Council, c/o National Kidney Foundation, 30 East 33rd Street, NY, NY 10016.

Name: ______________________________________________________________________________________

Address: _____________________________________________________________________________________

City, State, Zip: ______________________________________________________________________________

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☐ I am not interested in joining transAction Council but would like to continue receiving Transplant Chronicles at no charge.
John Harvey Jr., Faye’s husband, was a match for his father. John Harvey had experienced the miracle of transplant with Gayle and Faye, and he did not hesitate to proceed. All medical tests proved that father and son were a good match. Pup was reluctant, feeling he had lived out his life, but John Harvey would not take no for an answer. When he got the good news and the date was set, John Harvey called Pup and went to see him. After John Harvey gave him all the information, the two embraced in tears.

The many hours of prayer and thoughts about the transplant reached a climax on February 13, 1997, at Mercy Hospital in New Orleans, when John Harvey Jr. gave one of his kidneys to his father in a four-hour operation. Within a week, the two Robichauxs were walking together, adjusting to their new lives. Today, Pup is looking forward to swinging the driver and nine iron again and living in daily thanks to his son for such a monumental gift. John Harvey has resumed his job as a salesman and rides his bike with Faye, also a bicycle enthusiast, on weekends.

Faye and John Harvey felt honored by the opportunity to share parts of themselves to help others. Attitude, optimism and hope are the ingredients for successful transplant surgery, and John Harvey, Faye and the medical staffs at both hospitals certainly had those unique and special attributes. They gave Gayle and Pup a second chance at life.

Growth delay is common in children waiting for an organ transplant, due to the failure of the kidney, liver or heart. This growth delay is primarily caused by malnutrition from inadequate calorie and protein intake, higher calorie requirements, and protein loss in dialysis patients. Other factors that can contribute to growth delay in children with chronic renal failure are a calcium and phosphorus imbalance from lack of calcium and vitamin D in the diet; inadequate absorption of nutrients within the intestines; and resistance to growth hormone, a substance that is responsible for normal growth of bone and cartilage.

Growth in children is often delayed during the first 12 months after transplantation. This is apparently caused by high doses of certain anti-rejection medications, such as prednisone. Although long-term studies following transplantation show that children who receive liver and heart transplants often experience catch-up growth, this is not always true in children who receive kidney transplants. The North American Pediatric Renal Transplant Cooperative Study (NAPRTCS) demonstrated that children who receive a transplant before age one show the greatest improvement in growth over the next five years. Children who receive a transplant between ages one and five show improved growth, but to a lesser extent. Children who receive a kidney after age five do not show significant improvement in their growth.

Many strategies have been used to improve growth in children following a kidney transplant. One approach is to withdraw prednisone if a child remains rejection-free for six to 12 months after transplantation. Although some children show significant improvement in growth when prednisone is discontinued, others develop severe kidney rejection. Alternate-day dosing of prednisone has also been used to accelerate growth in these children. Several studies have demonstrated improved growth rates after one to two years of alternate-day therapy, without any harmful effects on the kidney.

Another strategy is daily injections of human growth hormone, which has been used in the last five years in selected children. Side effects from this drug, which are rare, include elevated blood sugar levels, bone deformities of the hips or mild elevations of the pressure within the brain. Growth hormone has been used in short children with various endocrine conditions. It has also been used successfully in malnourished adult dialysis patients to help them gain weight and control and improve their overall nutritional state.

Growth hormone is currently approved for use in children with chronic renal failure who have short stature; significant increases in growth rates have been shown following daily injections of this drug. Growth hormone has also been used successfully in many pediatric kidney transplant recipients, although other patients do not show any significant improvement. The effect of steroids, kidney function and age, as well as the growth rate prior to starting growth hormone therapy, may explain these differences. Additional concerns raised with the use of growth hormone are the risk of rejection and fear of worsening of kidney function.

A recently-reported French study to determine the safety and effectiveness of growth hormone therapy demonstrated a significant improvement in the growth rate of most children receiving this therapy. Three groups of children showed the best response: those who had higher growth rates prior to treatment, those with reduced function of their kidney transplant and those who received prednisone on alternate days rather than daily. Patients who had fewer than two episodes of rejection before starting growth hormone showed no significant increase in rejection risk. A similar study is currently underway in the United States.

Growth hormone therapy is a well-established treatment for children with chronic renal failure and short stature prior to transplantation.
Although several studies suggest that it is safe and effective in kidney transplant recipients with short stature, further long-term studies are needed before it becomes an accepted standard of therapy. Therefore, it is essential that children with short stature and their parents discuss these issues with their pediatric nephrologist and transplant surgeon when growth hormone therapy is being considered.
Remember how we used to play when we were kids? Memories of childhood bring me back to the days when my five siblings and I would jump out of bed early on a summer morning to meet our friends outside to play. And we would play from morning until evening. We couldn’t get enough of swinging on the leaves of the willow, jumping as far as we could and tumbling to our destinies.

It seemed we were never at a loss for something to do. It was a wonderful carefree time, without the stress and pressure that may go along with playing organized sports today. We were extremely active and physically fit, yet we did not have formal training, nor were any of our activities an organized sport (although I believe we were quite an organized group!)

Today, play is more complicated. Many children spend most of their recreational time playing organized sports. Whether they play T-ball, soccer, softball, baseball, track and field, volleyball or field hockey, it is usually organized through their school or an independent league.

If you have a child or a teen who has been transplanted, he or she might not participate in sports that much. Many children, and parents of children, who have had a transplant are under the impression that they should “take it easy” and not play sports or lead a physically active and challenging life. THIS IS NOT TRUE! After transplant, some patients may hesitate to exercise because they are unsure of what they can do and fear injury, rejection and harming their transplanted organ. However, your child can live a normal, quality life with a transplant. Just remember that he or she should avoid any direct hit to the transplanted organ and get a doctor’s permission before beginning any exercise or fitness activity. Then proceed with common sense!

Sports can help you or your child gain a renewed sense of control over life. So, which sports are best for your kids? It has been recommended that children should be introduced to a variety of sports when they are young so they can find one they like. Before age seven or eight, most kids are not ready for competitive sports. Many team sports involve bodily contact, which could be too tough on their bodies. At this age, the emphasis should be on basic skills, sportsman-like behavior and, most important, having fun!

The best time to introduce your child to team sports is between eight and 12 years of age. If your child chooses to play softball, volleyball, basketball or any sport where he or she might collide, bump or fall, you may want to take body size into consideration. It is important to keep in mind your child’s physical ability; you don’t want a situation that may destroy self confidence.

If your child is over 12, almost any sport is an option. It has been recommended that kids be at least 12 before they begin any long-distance running. Weight training has been a somewhat controversial subject, but the majority of experts seem to agree that 16 is an appropriate age for this activity.
It is critical to longevity and quality of life for your children to be active in various sports all year round. This will help them not only to maintain cardiovascular fitness and muscular strength, but will keep their bodies in good balance. Cross training (swimming, running, biking, weight training) can prevent overuse injuries, which usually occur in sports with repetitive actions.

If your child is not involved in a team sport or organized sport, there are alternatives. We still have roads and bikes and jump ropes. Children learn so many valuable lessons from the adults in their lives. Teach them by example! Choose a healthy lifestyle for yourself and include your children in it.

Here are some tips in looking for a safe fitness or organized sports program for your kids and helping them get the most out of it:

1. Choose a program that has clear policies on first aid and refers injured players for medical care.
2. Be sure the coaches are aware of your child’s medical condition.
3. Warm-ups and stretching should be done before exercise, and cool-downs and stretching should be done after exercise.
4. Make your child aware beforehand of the basic skills required and rules of the game.
5. Make sure your child wears protective gear.
6. Be sure that facilities and equipment are well maintained.
7. Never let your child play in pain.
8. Focus on successes, but don’t place too much emphasis on winning.

This Issue’s Hot Topic

There has been much controversy concerning organ allocation this past year. One recommendation is that if you receive a transplant at a center outside your local organ procurement organization (OPO) area, then the donated organ should have to accompany you from your OPO. Do you agree with this?

Call the Hot Topic hotline at (800) 622-9010 ext. 855 to leave your response.

Hot Topic Response (Issue 6:4)

Following is a sample of responses to the Hot Topic from last issue: Should a system for donor swapping be developed on a national level? Why?

I believe the donor exchange is a good idea with the shortage that we have. That way, if someone wanted to donate to save a relative but couldn’t do it, he or she could donate to someone else and still save the loved one.
International Athletes Compete in Winter Transplant Games

“I loved having the opportunity to spread the word about organ donation at the Winter World Transplant Games and to show that you can not only survive, but also be incredibly active after a transplant,” said Karen Couture, transplant athlete. “For me, it was quite a unique thing being a double lung recipient from Florida and competing at high altitudes.”

Karen was one of 62 competitors with a life-saving organ transplant vying for gold, silver and bronze medals in alpine and nordic skiing events at the III Winter World Transplant Games, held January 10-14 in Snowbird, Utah. The Winter World Transplant Games is an international competition celebrating the success of transplantation by showcasing the world’s best in transplant athletic alpine and nordic skiing and snowboarding. From the Opening Ceremonies to the final day of competition, athletes from around the world proved time and again that organ and tissue donation works.

Participating athletes came from Austria, Canada, the Czech Republic, Denmark, Finland, France, Germany, Great Britain, Hungary, Norway, Slovenia, Switzerland and the United States. “It was a wonderful experience to meet people from around the world,” said athlete and kidney transplant recipient Bob Skaggs of New Mexico. “It didn’t feel like we were competing against each other — we all cheered each other on. It was like being on one team.”

The feats of the athletes did not go unrecognized; awards were presented during the Closing Ceremonies. The Performance Challenge Cup is intended to honor the athletes who have demonstrated outstanding achievement at the Games. It went to three athletes: a 42-year-old kidney recipient, Walter Rettenger of Team Austria, who achieved the fastest finish times of all age groups and both sexes; Suzanne Knutti of Team Switzerland, who also posted the fastest finish times of all age categories in the women’s division, winning three gold medals in the giant slalom, parallel slalom and special slalom; and Jan Gunnar Skjelbek of Norway. The Fair Play Cup went to Bob Skaggs, who, at 62 years of age, was the second-oldest competitor. Bob dedicated his award to his donor, whose photograph he wore around his neck.

The Games were presented by the NKF under the auspices of the World Transplant Games Federation. The event was covered live via webcast by TransWeb at www.transweb.org. Coverage and competition results can be viewed on the NKF Website at www.kidney.org.

1999 WORLD TRANSPLANT GAMES MOVED TO BUDAPEST, HUNGARY

September 3-13, 1999

The World Transplant Games is the showcase for the finest athletic skill among the world’s transplant athletes. All eligible U.S. residents will compete as part of TEAM USA, which comprises 150 athletes who are selected on a first-come, first-served basis. World Games events include table tennis, track & field, squash, badminton, mini marathon, volleyball, tennis, golf, swimming, cycling, chess, fencing, and more!

For eligibility and costs, visit our website at www.kidney.org, or call the NKF at (800) 622-9010. For registration requests, call ext. 932 at the NKF or e-mail transplant@kidney.org.
In a finding that appears to support the federal government’s new organ allocation plan, the first report ever released on local waiting times shows that the length of time people wait for a transplant is directly affected by where he or she lives. For example, a liver patient with type O blood waits just 46 days in Iowa, compared with 721 days in western Pennsylvania.

Department of Health and Human Services (HHS) Secretary Donna Shalala used the results of the report, which was prepared by the United Network for Organ Sharing (UNOS), to bolster the government’s ongoing attempts to require that organs be allocated on the basis of medical need, not on where patients live.

“This report contains some of the strongest evidence yet that our nation’s organ transplantation system needs improvement,” Shalala said in a statement. “It makes clearer than ever that patients can be disadvantaged by the simple fact of where they live and at what transplant center they are listed.”

The seven-volume, 2,400 page report includes data on local waiting times for patients placed on a transplant waiting list during two periods: 1993 to 1995 for kidneys, and 1994 to 1996 for pancreas, kidney-pancreas, hearts, livers and lungs. The report also documents the number of registered patients transplanted, organ recovery rates from 1994 to 1996 for each OPO, and additions to and removals from waiting lists for each transplant program nationwide.

A spokesperson for UNOS, the leading adversary against changing the current system, which gives patients on a local waiting list first priority for an organ before it can be considered regionally or nationally, said the report findings are based on somewhat outdated information that is three to five years old.

“We see the report as a resource to give patients a rough idea of how long they may have to wait in a particular area,” the spokesperson said. “However, we think that changes we have made in the past two years have made a difference and that new data will show changes have taken place.”

HHS suggests the blame belongs with UNOS for not releasing data on waiting times in a timely fashion. “This report is a step forward, but it is still not the kind of timely and user-friendly information that patients and their physicians really need,” said Claude Earl Fox, MD, administrator of the Health Resources and Services Administration (HRSA), the government agency that oversees the day-to-day activities of UNOS. “Our goal is for future reports [from UNOS] to present more current information in a form that is more understandable for patients, their families and their physicians, including waiting time data for each transplant center.”

UNOS has taken steps to change its current bylaws to allow for releasing an expanded data report on a regular basis. A change in the bylaws was out for public comment, and the UNOS board was asked to vote on the changes. Assuming the changes are adopted, new up-to-date data should be available by June.

HHS regulations requiring UNOS to develop new policies that would help assure that organs go to patient with greatest medical need, in accordance with sound medical judgment and effective use of organs, are to take effect on October 21. Congressional legislation last fall delayed implementation of the regulation, which was issued in April 1998. The Institute of Medicine (IOM) is charged with reviewing the regulation proposal and will issue its findings in early summer.

Here is a region-by-region look at the current median wait that a patient with blood type O waited in 1994-1996 for a liver transplant. The nationwide median wait was 374 days.

REGION 1: Maine, Vermont, New Hampshire, Massachusetts, Connecticut, Rhode Island - 958 days.
IOM launches Congress-mandated comprehensive study of controversies surrounding U.S. organ allocation system

With the U.S. transplant community poised to undergo a fundamental overhaul of the organ allocation system, the federal government has launched a comprehensive study of the proposed new policy that would distribute organs on the basis of medical need, rather than geographic location.

The Institute of Medicine (IOM), facing an early summer deadline, announced it would hold three meetings of a newly-appointed committee that will make recommendations on the current controversies surrounding the organ allocation system in the U.S.

The Department of Health and Human Services' proposed regulation, which mandates that organs be allocated to the sickest patients first, based on common medical criteria and medical judgment, regardless of geographic location, is scheduled to go into effect on October 21.

The first of the hearings was held on March 11-12 in Washington, D.C., about five months after the IOM received the charge by the U.S. Congress, through the Government Accounting Office (GAO), to conduct a study to review "current policies of the Organ Procurement and Transplantation Network (OPTN) and the final rule."

The IOM study was a provision in a rider to the House Labor, Health and Human Services and Education Bill passed by Congress last October, which mandated a one-year moratorium on the Department of Health and Human Services regulation of the OPTN. The rider was tacked on to the legislation by Rep. Bob Livingston (R-LA), the short-lived speaker of the house, who resigned from Congress in January.

The IOM committee will examine the current system and the potential impact of the proposed regulations on:

1) "access to transplantation services for low-income populations and racial and ethnic minority groups, including the impact of state policies (under title XIX of the Social Security Act) regarding payment for services for patients outside of the states in which the patients reside;"

2) "organ donation rates and impact of broader sharing, i.e., based on medical criteria instead of geography, on donation rates;"

3) "waiting times for organ transplants, including a) determination specific to the various
geographic regions of the United States, and if practicable, waiting times for each transplant center by organ and medical status category, and b) impact of recent changes made by the OPTN in patient listing criteria and in measures of medical status:

4) “patient survival rates and organ failure rates leading to retransplantation, including variances by income status, ethnicity, gender, race or blood type; and

5) “costs of organ transplantation services.”

New Jersey residents who sign drivers’ licenses now added to state registry

Residents of New Jersey who sign their drivers’ licenses indicating their desire to be organ donors are now automatically registered as donors for the first time. Governor Christine Todd Whitman signed a new law that went into effect on February 25, which created the registry. New Jersey joined sister states Pennsylvania and Delaware as one of a handful of states in the U.S. with such a registry.

New Jersey residents who sign their licenses will have their wishes entered in their computerized drivers’ records, which can be accessed to determine if they are donors in the event of death.

“Our experience in Pennsylvania has demonstrated that official state registries can absolutely help increase organ donations,” said Howard Nathan, executive director of the Delaware Valley Transplant Program (DVTP), which services southern New Jersey, eastern Pennsylvania and Delaware.

The DVTP announced recently that it had the largest number of organ donations in 1998 for the third year in a row. A total of 298 area residents donated organs that resulted in 927 patients getting heart, kidney, liver, lung and pancreas transplants. It marked the fifth straight year that organ donations increased in the region, the DVTP said.

Increased incidence of cancer found with use of cyclosporine not a risk to transplant patients, experts say

The increased risk of cancer associated with the use of the immunosuppressant cyclosporine in transplant recipients appears to result from a direct effect on cells, not simply by impairment of the immune system.

“The high incidence of neoplasm and its aggressive progression, which are associated with immunosuppressive therapy, are thought to be due to the resulting impairment of the organ recipient’s immune-surveillance system,” explained Minoru Hojo, PhD, of Cornell University, and a multinational team in the February 11 issue of Nature. But the researchers said the drug also acts directly on tumor cells by increasing production of transforming growth factor-beta (TGF-b), a naturally occurring protein that induces tumor progression and metastasis.

The scientists found that cyclosporine appears to promote the growth of pre-existing tumors in mice with severely deficient immune systems. But when they blocked TGF-b with specific antibodies, it neutralized these drug effects and prevented the spread of tumors. Nonspecific antibodies had no such effect; however, the researchers believe this implicates cyclosporine-induced TGF-b production as the underlying mechanism responsible for tumor growth.

In an accompanying editorial, Gary Nabel, MD, of the University of Michigan in Ann Arbor, wrote that the study is “certainly provocative, calling into question the proposed mechanism by which cyclosporine induces secondary cancers.” But Nabel points out that several questions remain unanswered by Hojo’s study. In particular, he said it is unclear “...whether cyclosporine has a similar effect on precancerous cells, or whether it is involved in converting cells from a benign to a cancerous state.”

Nabel added that the study does not change the catch-22 that transplant physicians have recognized for years—transplant patients need new organs to survive, but cyclosporine, the drug that is key to preventing allograft rejection, also increases the risk of cancer. “The new observations do not alter this risk, nor do they suggest that any additional precautions be taken beyond those already recognized,” Nabel concluded. “But they do provide an insight into how these cancers come about and may be useful in treating them.”

Responding to the article, Geoff Cook, a spokesperson for Novartis, a manufacturer of cyclosporine, said the findings do not represent an increased risk to patients. “Cyclosporine is most often used to treat patients with life-threatening conditions. We think that the benefits are well-balanced in comparison to the risks.”
Heart transplant recipients benefit from exercise rehabilitation

Patients receiving heart transplants, like those undergoing coronary artery bypass surgery, are affected by preoperative inactivity and postoperative deconditioning, and can potentially benefit from exercise rehabilitation.

Researchers at the University of California at Los Angeles (UCLA) and the West Los Angeles Veterans Affairs Medical Center prospectively studied 27 heart transplant patients randomly assigned to participate in a six-month structured cardiac rehabilitation program (study group; 14 patients) or to undergo unstructured therapy at home (control group; 13 patients). They found that exercise training was well tolerated by the study patients; it increased overall exercise capacity and did not increase the incidence of rejection.

“The practical implications of these results are that improved work capacity can be achieved in a structured, individualized exercise program,” wrote Jon Kobashigawa, MD, and his co-authors. “By implication, increased exercise capacity may lead to participation in more strenuous activities and thus to a better quality of life, since more activities can be performed.”

The authors speculate that concern about whether the denervated transplanted heart can tolerate the physiologic stress of exercise training and fears that exercise might precipitate acute rejection of the transplant may underlie the reluctance to prescribe exercise training after transplantation. While they concede that the small size of their study limits the strength of the results, they contend the end points of exercise capacity are relatively objective and suggest important differences between the study and control groups. Based on their findings, the researchers conclude “exercise training should be considered standard postoperative care for heart transplant recipients.”

Jury finds Aetna guilty of refusing to pay for BMT treatments, awards woman record $120.5 million

A California woman who claimed her HMO withheld coverage for bone marrow treatments for her cancer-stricken husband has received the largest jury award ever given in the U.S.—$120.5 million.

Teresa Goodrich of San Bernadino sued Aetna U.S. Health Care for wrongful death, claiming the company refused to pay for treatment its own physicians recommended at a hospital outside the plan’s network. The jury found that Aetna has committed “malice, oppression and fraud,” and contributed to the shortening of her husband David’s life.

The jury awarded $116 in punitive damages and $4.5 million for medical expenses and loss of companionship. Lawyers said the award was by far the largest in the U.S. ever against an HMO for denying health care. The previous record was a $89.3 million in 1993 against HealthNet, also for refusing to pay for a bone marrow transplant.

Aetna said it will appeal the jury’s decision. However, the company announced that beginning in July, its six million members will be able to appeal insurance coverage denials to committees of independent physicians, and Aetna said it will abide by the decisions.

Use of ATG increases risk of CMV infection during early post-kidney transplant period, Chinese report

Use of the immunosuppressant antithymocyte globulin (ATG) increases the risk of cytomegalovirus (CMV) infection and disease during the early post-transplant period among cadaveric kidney recipients, according to Chinese researchers.

David Chong-wah Siu, MD, and his colleagues at Queen Mary Hospital in Hong Kong retrospectively studied 116 patients given cadaveric kidney allografts from 1983 to 1998. The investigators observed a statistically significant association between the use of ATG within the first month following renal transplantation and the development of CMV infection during the first 90 days after surgery. Thirty-four patients developed CMV infection, and 11 patients developed CMV disease. Eighteen of the 34 patients with CMV infection and nine of the 11 with CMV disease had received ATG.

“These associations persisted on logical regression analysis, taking into account other variables such as demographics and the use of other immunosuppressive agents [cyclosporine or azathioprine],” said Siu.

Siu plans on re-analyzing the data by categorizing patients who received different combinations of immunosuppressants, but he believes the conclusion that ATG is a risk factor for CMV infection is firm. “. . . If anything, [the reanalysis] will make the observation more significant,” he predicted.
Most of us have had some experience with children who don’t want to eat what is on their plates. We call them “picky” and often just let them have their way to avoid a fight at the dinner table and to get them to eat something, no matter what it is. One thing to remember if you are trying to feed a picky eater is that children will eat different amounts from day to day. It is important to watch your child’s growth over a period of months. He or she is eating enough if growth is keeping up with the growth curve according to your pediatrician.

It is also important to start teaching healthy eating habits to children in their early years. However, this can be the most difficult time to get them to try a variety of foods. The following suggestions may help you solve some of your picky eater’s problems and help avoid those food battles:

- **It is very important for children to have routine and structure in their lives, and this also applies to eating.** Toddlers who are offered scheduled meals and snacks, and are not allowed food or caloric beverages (such as juice or soda) in between, eat up to 1 1/2 times more than those allowed to snack as much as they want. Plan meals and snacks two to three hours apart and offer them in the same place each time.

- **Avoid giving too many beverages, such as juice, soda and milk, between meals; they can make a child feel full.** Serve milk and juice with meals and snacks, and if a child is thirsty between meals, serve water. Limit juice to no more than four to eight ounces daily.

- **If your child has had a transplant or has had trouble gaining weight, it is tempting to let him or her eat any food at any time. Resist the urge to push the child to eat or drink all day; he or she won’t feel hungry at meal or snack time and will decrease the total food intake.**

- **You may need to offer a new food 10 to 15 times before a child accepts it and learns to like the food.** Ask your child to take one bite of a new food each time it is offered, but don’t force the food if he or she doesn’t like it.

- **Serve small portions.** One serving is equal to one tablespoon of food for each year of age. Large portions can be overwhelming. Let your child ask for more.

- **Pushing or forcing a child to eat is a sure way to create an eating problem.** Make meal times a pleasant experience. Turn off the television and sit down at the table as a family. Allow your child to eat one food at a time at his or her own pace.

- **Let children help you prepare the meal.** Give age-appropriate chores. Even a toddler can tear up lettuce, scoop mashed potatoes, set the table and help clean up.

- **Let your child help plan a meal once a week.** At mealtime, remind him or her who chose the meal.

- **If vegetables are a problem, try disguising them.** Add pureed vegetables to ground beef in hamburgers, spaghetti, meatballs, lasagna and casseroles. Add zucchini to baked goods such as breads and pancakes. Grate carrots into peanut butter and spaghetti sauce.

- **Above all else, remember that you control what food comes into the house, when the food is offered and where it is eaten.** Your child controls if food is eaten, what is eaten from the food offered and how much is eaten.

- **If your child has had a lot of medical problems, such as long-term ventilator support, tracheotomy, nasogastric tube, or eating has been painful in the past, therapy may be needed to help with eating.** Contact your doctor for a referral to a dietitian, speech therapist or occupational therapist.

Angie is a clinical dietitian in the pediatric gastroenterology department at University Hospital, Nebraska Health Systems.
hepatitis B is an infection with a virus that usually affects the liver. It is the most common chronic infection in the world and a major public health problem, yet it is easily preventable. Over three million people worldwide are infected with the hepatitis B virus, mostly in Africa or Asia. However, over 1.2 million people in the United States are infected with the virus; there are more than 300,000 acute infections with the hepatitis B virus each year in the United States.

Infections with the hepatitis B virus can spread from person to person either through contaminated blood or blood products, or by the exchange of body fluids. Hepatitis B virus is present in saliva, tears, semen, vaginal secretions and breast milk.

Risk factors for contracting hepatitis B include getting contaminated blood or blood products by sharing unsterilized needles, getting tattoos or body piercings, and accidentally receiving contaminated blood in the health care setting. Even such things as the splashing of blood in the eyes or sharing toothbrushes or razors can result in the transmission of hepatitis B from one person to another. Infected mothers can transmit the virus to their children and, unfortunately, most of these children will have the virus for life. It can be spread through both heterosexual and homosexual contact. However, unlike the hepatitis A virus, which can be spread through contaminated food products, hepatitis B is rarely spread in this way.

Infections with the hepatitis B virus usually present themselves in one of four ways, which is influenced by the age, sex and immune status of the individual who gets the infection. Most cases of acute hepatitis B infection are associated with a relatively mild illness, sometimes with the development of jaundice.

Most patients will recover from this illness, and will then be immune to the hepatitis B infection. However, some patients do not completely recover from the infection and have the hepatitis B virus in their bodies forever. This second group of patients are called chronic carriers and may go on to develop liver cirrhosis and require liver transplantation. The vast majority of infants who develop acute hepatitis B infections will become chronic carriers, while only one to five percent of adults who are infected with hepatitis B virus will become chronic carriers.

The third type of hepatitis B infection is called sub-acute hepatic necrosis. The infection is more severe, and patients develop significant liver injury and may require long hospital stays. Some of these patients may even develop enough liver injury to require urgent liver transplantation.

The least common type of infection with hepatitis B virus is called fulminant hepatic failure, which results in severe liver injury from which the patient may recover fully, or may require liver transplantation or even die.

The diagnosis of hepatitis B infection is made by a series of blood tests that check both for the virus itself and for antibodies that have been formed in a reaction to the virus. Through these blood tests, physicians can determine those patients who have had the infection and are cured (immune to the virus); those patients who have had the infection and are chronic carriers; and those patients who have very active viral hepatitis B infection in their livers. Tests are also available to actually check for the presence of the DNA from this virus in the blood; additionally, liver tissue can be stained for the presence of the virus.

The single most important thing to understand about the hepatitis B infection is that it can be prevented with a highly effective vaccine given as a series of three injections spaced over a period of several months. It is recommended that all children receive this vaccination shortly after birth. All adults should also be vaccinated as a precaution in case they are ever exposed to the virus. At a minimum, anyone associated with transplantation or dialysis, or working in the health care setting, should be vaccinated to prevent an infection with a virus. In theory, it would be possible to eliminate this infection within one generation if all individuals were vaccinated.
In addition to the vaccine, there is the hepatitis B immunoglobulin, used to treat individuals who have been exposed to the hepatitis B virus. This is often done in conjunction with vaccination in individuals who have received a contaminated needle stick or blood that may have been contaminated. Unlike the vaccination, which provides protection against future infections, the immunoglobulin is used to try to prevent infection in known high-risk situations. It does not offer long-term immunity to the hepatitis B virus.

Finally, there are treatments available for patients who develop chronic hepatitis B infection. However, because these medications only control but do not cure the infection, patients who stop these medications will most often develop a recurrence of active hepatitis B infection. Also, in some patients, the virus changes to a strain that is not sensitive to the medication. A true cure for hepatitis B will require better antiviral medications.
At the start of the allocation debate that has unfolded over the past year, the Department of Health and Human Services (DHHS) proposed a goal of increasing organ donation by 20 percent. Since then, early signs are that the country has seen a five-and-a-half percent increase. By my calculations, that leaves 15 percent to go. Therefore, a 15 percent increase in the next year is unlikely.

The one measure that probably influenced the increase over the past year (the largest increase since 1993) was the Medicare Hospital Conditions of Participation, which were a big accomplishment for DHHS. These regulations, which were not easy to put into place, will probably do more for organ donation than any other single action over the past few years. These conditions mandate that all deaths in hospitals be reported to the local OPO, or fines will be assessed and the hospital’s Medicare license revoked. The effectiveness of public education in increasing organ donation is hard to measure and, as far as some are concerned, nonexistent.1

I believe that an additional 12 percent increase in donations could result from reducing medical examiner denials.2 Despite widespread attention in 1994 given to organ donor losses due to medical examiner denials, many areas of the country still needlessly lose significant numbers of organ donors because a local medical examiner, coroner or justice of the peace refuses to release the organs of potential donors. In fact, early data indicate that the problem has not gotten any better since 1992. The United Network for Organ Sharing Scientific Registry tracks organ donors lost to medical examiner denials and, although it has not yet been published, early data seem to support the 11.4 percent number for 1992, which was published in the Journal of the American Medical Association (JAMA) in 1994. (This means that of all U.S. potential organ donors, 11.4 percent were denied recovery in 1992, possibly denying life-saving transplants to, conservatively, 2,979 people on the waiting list.)

This is particularly a problem with potential pediatric organ donors who have died due to suspected child abuse or sudden infant death syndrome (SIDS). Medical examiner denial is likely one of the major contributing reasons for the pediatric death rate on the waiting list for a liver transplant in children age five and under. (See figure below.)

Medical examiners and coroners could significantly increase organ recovery in the United States if cases falling under their jurisdiction, after appropriate examination, were routinely released for organ recovery and transplantation.

It is a crucial public policy issue that the supply of organs and tissues for transplantation be maximized. To improve the situation, Congress ordered hospitals to come up with protocols requiring that families of all those who die in hospitals be requested to donate organs. But one source of donated organs that could be tapped immediately are those lost through medical examiner denial of organ recovery. The government could take a leadership role by passing legislation requiring routine, timely and unobstructed release of all potential organ donors by medical examiners.

While this federal legislation would have to work in conjunction with state laws, it most certainly would lead states to pass laws that make it impossible for medical examiners to block the recovery of life-saving organs. Some states have already taken such steps. Texas passed legislation in 1995 requiring medical examiners to release organs for transplantation unless the medical examiner was physically unable to do so.

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present in surgery viewing the organ in question.

The conclusions made in the 1994 paper have not changed, but it is now 1998 and they need to be repeated: Organ donation is NEVER incompatible with forensic investigation. The two can occur in harmony, with medical examiners performing their crucial role in determining the cause and manner of death, and every transplantable organ being recovered and transplanted. These goals are not mutually exclusive.

We have also heard over the past year that geography should not influence who lives or dies for lack of an organ. I agree, but for a different reason than the one cited by Secretary Shalala and the large transplant centers attempting to influence organ allocation. Geography plays a big role because in some areas of the country organs are routinely released by medical examiners and in others they are not. Should someone’s life depend upon arbitrary and inconsistent practice when it comes to organ loss due to medical examiner denials. There’s a big pool of potential donors out there that would be easy to tap. With the necessary education and legislation, the donor pool can be increased.

Note: For brevity’s sake, whenever medical examiner is mentioned in this article, it means medical examiner, coroner or justice of the peace.


More than Just a Valentine

Hundreds of living organ donors in the Delaware Valley celebrated Valentine’s Day on February 13th at a luncheon at the Adam’s Mark Hotel. “The Celebration of Life” honored Delaware Valley residents who have given the gift of life by becoming living organ donors. Over 300 organ donors, recipients, transplant professionals and guests gathered for lunch and a presentation by keynote speaker Kenneth P. Moritsugu, MD, U.S. deputy surgeon general. As part of the program, Mayor Ed Rendell also spoke, stating that February 13, 1999, was a day to recognize the heroic act of living donors.

Living donors received certificates of appreciation and Gift of Life pins. The event, organized by a committee of non-profit organizations and transplant facilities, was chaired by Shuin-Lin Yang, MD. Dr. Yang said, “In my 20 years as a transplant surgeon, I’ve witnessed some amazing advances in medical technology, but nothing is more awe-inspiring, more worthy of accolades or more humbling than the living organ donors. They are the true heroes of many transplant stories.”
In preparing to write this article, I spoke with many transplant recipients, people waiting for a transplant, friends and family members about their thoughts and experiences. I discovered there are several points of common ground surrounding the “transplant experience.”

The first common point is the range of emotions that many of us feel. Most people agreed that their transplant was one of the most, if not the most, “emotional roller coaster” events of their lives. People who had received more than one transplant over time stated that even though they knew most of what was happening by the second or third time around, the emotions were still marked by extreme highs and lows. And not all of these feelings were experienced before the transplant. Many did not surface until well into or after the recovery period.

Common thoughts were about life and death, and not only our own, but of the donor and his or her family. Many of us wondered about the welfare of family and friends if we did not make it, and even thought that maybe they would be better off if we just died. Many patients with kidney failure who were stable on dialysis expressed a lot of concerns about whether a transplant would be worth the risk of surgery and regimen of immunosuppressive drugs and side effects that follow. Obviously, those patients who needed a liver, heart or other organ, with no replacement therapy available, had different thoughts.

Family members and friends shared many of these thoughts from a slightly different perspective. Many of them were always trying to help the person with the illness, with no regard for the emotional burden they were putting on themselves. Others found themselves drifting away from the person, either out of fear or in an attempt to protect themselves from being hurt.

The second common point was related to concerns about physical well-being and post-transplant capabilities. Many people had been sick for a long period of time. After a successful transplant, they were hesitant to push themselves to do any physical activity. This withdrawal can lead to further physical debilitation, continued unemployment, and living life in a dependent mode. Others seemed to take their newly found physical vitality and pack everything they had missed in the pre-transplant years into a short period of time. This strategy can take a high physical toll as well. It is necessary to merge these perspectives and embrace one that focuses on balance, pace and moderation.

The third point of common ground involved views on the future. While no one can tell what is over the horizon, the key seemed to be moving on, “living for the moment” and appreciating the important things in life. This attitude must be balanced by setting and working toward long-term goals. For some this may mean returning to work, while for others it may mean giving of themselves and their time in unselfish ways for the improvement of society. We have taken from the system, family and friends to get to this point in our lives, and now we need to learn to be givers again. Vision, foresight and consideration seem to be the words that are appropriate in this effort.

I’d like to add my own perspective on the transplant experience. Despite our situation, we can get out of life what we put into it. We have a unique viewpoint. We have seen life from its highest and lowest points, something many “healthy” people never do. This presents us with a unique opportunity. Family and friends can play a big role here, but the ultimate responsibility for our course in life starts with us as individuals. It can be tough at times, but if we maintain the right perspective, we can be productive members of society with a tremendous sense of accomplishment and self-worth. If you don’t believe me, come to the next U.S. Transplant Games. Take the time to meet the athletes and donor families and hear their stories of tragedy and triumph. It sure helped put things in perspective for me.
My name is Jim Nyilas Jr. My story begins when I was diagnosed with juvenile diabetes at the age of eight. Now I am 33 years old, and I look back and wonder how I ever survived as long as I did. It was hard to live a completely normal life, always falling behind as I tried to keep up with my peers, both physically and mentally. I had been told all of my life that I had an incurable disease, and I always wondered when it would claim my life. This left me with no hope for a solid future. Life just had no particular meaning for me.

In September 1995, diabetes finally turned on me. Having already lost half of my eyesight, I was diagnosed with kidney failure, a common complication of diabetes. I spent six months on peritoneal dialysis, fighting for my life and losing quickly. By May 1996, I was unable to walk more than a few steps without collapsing. In June 1996, after being told that I had no time left, I realized that I did not want to die. I turned to God and pleaded for my life. I then received a call from a transplant coordinator at Our Lady of Lourdes Medical Center in Camden, NJ. A donor kidney had been found, and I had the transplant surgery. While the transplant was a success, I was not out of the woods yet. Adjustments had to be made from time to time, not only in medications, but in everyday life.

After the transplant, I tried to contact the family of my donor following standard protocol set by the procurement center. While filling out a Christmas card, I phoned the center to ask if I could send a photo to the family. I learned that the center was trying to contact me, too, to let me know of my donor family’s desire to meet me. On January 4, 1998, I met with the Ramos family at their home in North Jersey. It was then that I learned so much about my donor, Helio Ramos, a 15-year-old young man who lost his life as the young victim of gunfire. He lived as the perfect role model for today’s youth. Helio’s family came to America in 1985 from Portugal, just before Helio started kindergarten. He was in the early years of high school when this tragedy struck. Helio was brought back to Portugal where he was laid to rest.

During one of my many visits with the Ramos family, I was asked if I would be interested in being interviewed by the Portuguese community newspaper, Luso Americano. I was more than happy to do so. I was told that 300,000 readers got the story. Shortly after, on June 23, 1998, I was a guest speaker at what would have been Helio’s high school graduation. I felt I must attend to allow Helio to graduate, even if only in spirit. I will never forget the experience when more than 2,100 people went from deathly quiet to a roaring standing ovation as I introduced Helio’s family, who joined me at the podium that night. These are just a few of the many great experiences that I have shared with the Ramos family. The love shared and expressed by our families is unmatched!

I am now working on returning to school to get a counseling degree while volunteering as a peer counselor for Atlantic City Medical Center’s dialysis unit. I always look forward to giving hope where I can, especially to those who suffer as I did. I also take every chance I can to promote organ and tissue donation through volunteer awareness programs with the Cape Atlantic Transplant Support Group in South Jersey under the direction of the Delaware Valley Transplant Program based in Philadelphia.

I have many to thank, and foremost is God for taking every step of this journey with me. Also, I must thank my family and the Ramos family, my nephrologist and the dialysis unit staff, the transplant coordinators, my home nurse and physical therapists, my church and everyone who gave me the support to be healthy.
My name is Sarah Luca and I had a kidney transplant four and a half years ago. I found that the things that got me through it were a positive attitude and a sense of humor. It’s a lot easier to get through things being happy rather than always looking on the bad side. It’s not always easy, though, especially when you’re on prednisone. Prednisone gives people mood swings so sometimes instead of smiling, you just want to burst into tears. But you shouldn’t worry, because that eventually goes away. Having a positive attitude will help you get well sooner.

It is also important that the people around you try to be upbeat and cheerful, too, because it will make the whole atmosphere better. It’s hard not to think about what may go wrong, if anything, to not always be worried and not panic every time you have a headache. All I can say, though, is it’s a whole lot easier to be happy and take each day at a time and see what it brings.

Another thing that you really need to have when going through a transplant is a sense of humor. Without mine, I probably never would have lasted. It’s a bit tough, though, because sometimes you get puffy in the face or hairy, and some people may make fun of you. If you turn around the insult and make it into a joke, then you will feel a whole lot better. For example, one time I was babysitting and the little girl said, “Man, your arms are really hairy!” I replied, “Yep, that’s right — just like a gorilla that is real hungry. You had better run because I’m going to get you.” And I started chasing her. We laughed, and it felt good that I could joke about it.

You also need to remember that this is a small price to pay in order to have a healthy life. So just keep in mind, be positive and keep a sense of humor.

Sarah Luca is 14 years old, from Attleboro, Massachusetts. She received a kidney from her uncle.