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TRANSPLANTS

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A GENETIC LEGACY
What would you do to
save your brother's life?

**REGENERATIVE
MEDICINE**
Changing the future
of transplants

THE GIFT OF LIFE

Actress **Katherine Heigl**
opens up about the importance
of being an organ donor.

PHOTO: JOHN RUSSO

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CHALLENGES

With the support of the American public, **advancements in organ transplantation** will continue to restore hope for those waiting to survive.

Do you believe in miracles?



Daniel R. Salomon, M.D.
PRESIDENT, AMERICAN
SOCIETY OF TRANPLANTATION

“It’s possible to develop new mobile apps that will significantly improve survival rates by directly engaging patients in their drug therapy.”

The word ‘miracle’ is thrown around casually, often referring to everyday occurrences like confirming a reservation or making it to a meeting on time. In the field of medicine though, organ transplantation is something truly miraculous — cheating death and restoring hope to thousands of Americans suffering from the failure of their kidneys, livers, hearts or lungs.

Sobering facts

Nearly half of all transplanted organs will fail within 10 years. Our patients will either die of their original disease, or require a second transplant — a much more challenging and risky procedure. The primary objective of the American Society of Transplantation (AST) is to restore the health of our patients and ensure the long-term survival of those who have undergone transplantation.

Why do so many transplants

fail? Chronic rejection is caused by the immune system’s destructive response to a transplant, and powerful drugs must be taken to prevent that from happening. But therapy isn’t a few short weeks, it’s for life. And because these drugs have toxicities that complicate the choices physicians must make after a transplant, it’s often a difficult process.

Overcoming obstacles

We must develop a new generation of drugs that are safer and more effective; we must develop new tests to help doctors monitor and optimize drug therapy for each individual patient, and we must create an environment for the transplant so that rejection is taken off the table forever. It’s possible to develop new mobile apps that will significantly improve survival rates by directly engaging patients in their drug therapy. It’s possible to engineer new organs using stem cells that have been genetically modified to suppress organ rejection. All of

this is possible, but only if we have the necessary support.

Established by AST, the new Transplantation and Immunology Research Network (T.I.R.N.) includes hundreds of physicians and scientists who have dedicated their lives to advancing the research necessary to change lives. Organ transplantation has always been at the intersection of all science and medicine. Thus, transplantation research also contributes to fundamental understandings of immunity to infections like HIV, to autoimmune diseases such as multiple sclerosis and diabetes, and to the blood vessel inflammation that causes heart disease.

But no enterprise can function without funding. These are tough times, and we need the support of the American public to have any chance. There’s only one question: Do you believe in miracles?

DANIEL R. SALOMON, M.D.
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EDITOR’S PICK



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Hand and face:
A new era of transplants



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**MEDIA
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INSIGHT

NEWS IN BRIEF

Thanking our nurses

A transplant takes a team of skilled health-care professionals

Transplant nurses around the world have specialized knowledge, skills and abilities to care for living and deceased organ donors and their families, organ transplant recipients and their families, and organ transplant communities. Because transplantation is constantly changing with new treatments, techniques and technologies, the transplant nurse has a love of life-long learning and is always pushing to know more about providing excellent care for those who give and receive



**Cindy Russell, PhD
RN ACNS-
BC FAAN**

PRESIDENT,
ITNS

organs. The International Transplant Nurses Society, the professional organization for transplant nurses, promotes the education and clinical practice excellence of nurses who are interested in and participate in the care of solid organ transplant patients. Transplant nurses make up 'One World of Caring'.

**CINDY RUSSELL,
PHD RN ACNS-BC FAAN**
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MIRACLE MATCHMAKER

Tens of thousands of people in the United States get successful kidney transplants each year.

An improved kidney matching system will take effect in late 2014. It will help more people have longer function with their transplanted kidney. It will also shorten the wait for some groups of people who often wait a very long time because they are hard to match with most kidneys.

Transplant candidates will not lose credit for any time already spent waiting, which

is a major factor in kidney allocation. Patients who began dialysis before being listed for a transplant will have their waiting time backdated to their first dialysis date.

People who will need a kidney for a longer time will be matched more often with kidneys that have the longest expected function. Kidneys that may last a shorter time will be more readily available for people who have difficulty remaining on dialysis.

BRIAN M. SHEPARD
CEO, UNITED NETWORK
FOR ORGAN SHARING
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Gift of Life Donor Program is celebrating 40 years of giving others a second chance at life.

Gift of Life Donor Program



Gift of Life Family House



Gift of Life Institute



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CHANCE

40
YEARS

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1974 - 2014

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A Donate Life Organization

INSPIRATION

TWO BROTHERS, ONE LIVER

Live-donor liver transplantation is a lifesaving option.

Jack and Gene Johnston share many things — their parents, their family history and their love of warm weather destinations — especially all-inclusive Caribbean getaways, where they can swim, snorkel, hang out on the beach and enjoy oceanfront dining with their wives. However, they have had very different health experiences. Jack, 56, was born deficient in the liver protein, alpha-1 antitrypsin. Both of his parents are genetic carriers. Two of his siblings, including his twin brother and his sister, are also carriers; however, his brother Gene, 52, is not.

Alpha-1 antitrypsin deficiency is an inherited disorder that can lead to lung and liver disease, with symptoms first appearing between ages 20 and 50. The main symptoms are shortness of breath, fatigue and recurring respiratory infections, which eventually develop into more severe illnesses, including acute liver and/or respiratory failure.

A family's fight

About 12 years ago, Jack started experiencing difficulty breathing, excruciating stomach pain and fatigue. After his diagnosis, Jack became progressively sicker, until



FAMILY FUN UNDER THE SUN
The Johnston brothers Gene (left) and Jack (right) love to travel with their wives, Dianna and Julie. Next up, the Bahamas in November.
PHOTO: JULIE JOHNSTON

finally, in June 2013, it was clear that his liver was failing. Gene says, "We were on vacation in the Dominican Republic and Jack was clearly in a lot of pain."

Gene called the hospital, where

Jack was being treated, and was invited in for extensive testing. Because of his matching genetic profile and good health, he was deemed a suitable living organ donor for Jack, who was surprised when Gene approached him about being his donor. With family encouragement, Gene and Jack prepared themselves for a transplantation process in which Jack's liver would be removed entirely and part of Gene's liver would be transplanted into his brother.

New beginnings

On January 14, 2014, the two brothers underwent surgery. Gene was on the operating table for 11

hours, while Jack underwent a 16-hour procedure. Both brothers recovered quickly. Jack now takes immunosuppressants and has some water retention (which is decreasing daily), but these are small inconveniences to him. "I feel great!" he says.

November 2014 promises to be a good time for the Johnston brothers and their wives — They're heading to the Bahamas. Though Jack says he will have to be careful of the sun (a must for transplant recipients), he's counting on lots of time snorkeling with his brother — and celebrating beachside with his entire family.

NICOLE GRAY

editorial@mediaplanet.com



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NEWS

A PROMISING FUTURE FOR KIDNEY TRANSPLANT RECIPIENTS

According to statistics from the National Kidney Foundation, there are almost 100,000 patients with end-stage renal disease (ESRD) waiting to receive a kidney. In 2013, more than 14,000 patients received kidneys through transplants from donors. They are the lucky ones.

The next generation of medication

Getting a new kidney is only the first step towards full recovery. Equally important is the follow-up immunosuppressive regimen. The therapeutic goal is to decrease immune response enough to prevent organ rejection, while minimizing side effects. Currently being used are medica-

tions including cyclosporine, steroids, nephrotoxicity, tremors and other serious side effects. Researchers are constantly working to deliver easier to use medications, and their work is paying off.

“Researchers are constantly working to deliver easier to use medications, and their work is paying off.”

The most commonly used CNI, tacrolimus, was approved by the FDA in 1994, and has been used successfully to prevent acute rejection in both liver and kidney transplant patients. Unfortunately, high doses of tacrolimus are associated with hypertension, hyperglycemia, insomnia,

to use medications, and their work is paying off.

There is now a once-daily formula of tacrolimus, featuring a special technology that makes it easier to take, and can be taken at lower doses with comparable results. According to John Weinberg, MD, Executive Vice President and Chief Operating Officer of Veloxis Pharmaceuticals, “Once daily

formulations with lifelong therapy makes it easier for patients, with less toxicity and a better experience overall.”

Future solutions

Regardless of which combination of medications a patient takes, daily adherence is critical. Missing one dose could lead to organ failure. However, the good news is that over time, regimens continue to get easier as new treatment options are introduced.

NICOLE GRAY

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INSIGHT

ASK THE EXPERT



Developing new therapies

Cell therapy expert Thomas Fellner, PhD., MBA, discusses how we're genetically reprogramming cells to create new cells.

Question: Dr. Shinya Yamanaka at Kyoto University in Japan was the first to generate induced Pluripotent Stem Cells (iPSCs). He later was awarded the Nobel Prize for Medicine or Physiology for his work. What is the significance of this discovery?

Answer: Embryonic Stem Cells (ESCs) can become any cell type in the human body. It was thought that these cells would revolutionize medicine and the treatment of disease. Despite this potential, the use of embryo-derived cells has been controversial. Dr. Yamanaka's discovery allows researchers to genetically reprogram adult cells to create new cells, with the same properties as ESCs, without the same ethical and moral concerns.

Q: What impact will iPSCs have on the development of new therapies and pharmaceutical drugs?

A: While iPSC derived cell therapies are a few years from clinical testing, considerable progress has been made in the development of treatments for age-related macular degeneration, Parkinson's disease and diabetes. Additionally, they have spurred on advancements in disease modeling and drug discovery. Given the profound potential of iPSCs in regenerative medicine, they have become a key focus in both academic and commercial organizations alike.

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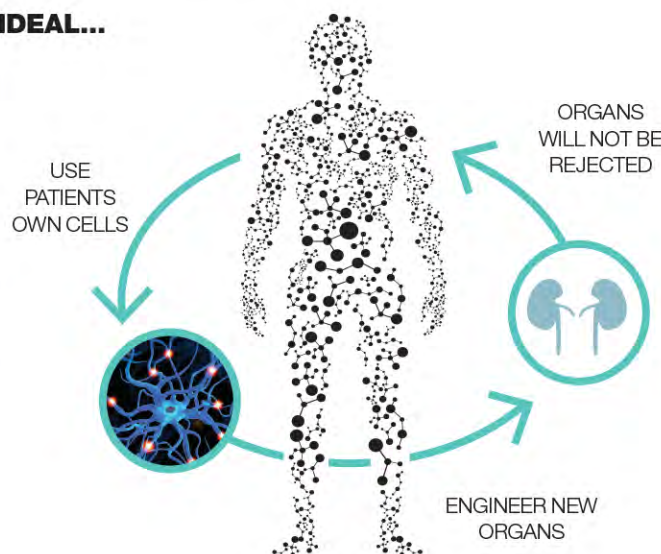
Regenerative Medicine

THE FUTURE OF TRANSPLANTATION

FACT...

There are currently more than **122,000** people on the U.S. waiting list for an organ transplant and nowhere near enough donors to meet their needs. The ultimate goal of regenerative medicine is to develop organs and tissues in the laboratory to help solve this shortage.

IDEAL...



IN CONCLUSION...

It is much too soon to predict whether we'll be successful growing all organs and whether the need for organ donation can eventually be eliminated.

LEVELS OF ORGAN COMPLEXITY

Scientists have successfully engineered and implanted organs from the first three levels in humans.

LEVEL I
FLAT STRUCTURES
The least difficult are flat structures such as the skin.

LEVEL II
TUBULAR STRUCTURES
Tubular structures that act as conduits, such as blood vessels and urine tubes.

LEVEL III
HOLLOW ORGANS
The next level is hollow organs, such as the bladder.

LEVEL IV
SOLID ORGANS
Solid organs such as the heart, kidney, pancreas and liver are very dense with cells and require a rich supply of oxygen to survive.

Source:
Wake Forest Institute for Regenerative Medicine
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A HELPING HAND
Double-hand recipient Lindsay Ess serves as the patient representative on the committee developing policies for face and hand transplants.

PHOTO: IMAGE MACHINE LLC

More than just internal organs

A committee of VCA experts develop national policies and procedures for those in need of a hand or face transplant.

As of July 2014, face and hand transplants — also known as vascular composite allografts or VCAs — will be considered organs by the federal government. The same kind of rules that cover the allocation of kidneys, livers, hearts, lungs, pancreas and intestines are being developed for VCA transplants. United Network for Organ Sharing, the non-profit organization that runs the nation’s transplant system, formed a committee of VCA experts to develop national policies and procedures to ensure that all patients who need a hand or face transplant are considered fairly, and that we maintain the best possible outcomes for recipients. UNOS’ board will vote on the committee’s initial recommendations on June 23, so that initial policies will be in place when the federal regulation goes into effect. These policy areas include additional informed consent by donor families and a process to match donors with candidates based on how long patients have waited.

SUE V. McDIARMID M.D., CHAIR, OPTN/UNOS VASCULARIZED COMPOSITE ALLOGRAFT TRANSPLANTATION COMMITTEE
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BEST TIPS

Why the long wait?
Dr. Sridhar Tayur, owner of OrganJet, explains how to list smartly

Question: How can transplant patients benefit from “listing smartly?”

Answer: There are two main considerations beyond cost: outcomes, that ensure a good and long post-transplant life, and wait times to obtain a transplant. By selecting a transplant center “smartly,” patients can reduce their wait times and improve outcomes.

Q: How does geographical location affect an organ transplant?

A: The wait times are strongly correlated to geography. In NY/NJ, Boston, Atlanta, Chicago and LA, the wait times for kidney and liver transplants are very high compared to those at centers elsewhere. Patients in the high wait areas can list in a center with low wait in other geographies, depending on their insurance coverage and ability to travel or move.

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“When I think about where John is now...I can smile. He’s making a difference.”

- Jayne, wife of donor



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INSPIRATION



Saving the lives of others

After a tragic accident, actress Katherine Heigl's family donated the organs of her late brother, saving the lives of five people.

Mediaplanet Why is organ donation something you are passionate about?

Katherine Heigl Organ dona-

tion has always been a very close subject to my heart as my brother Jason was a donor. A tragic accident left my brother with a mas-

sive brain injury, but he was fine from the neck down. Through this difficult and tragic experience, our whole family learned that as hu-

man beings we need to have as much compassion for others as we have for ourselves. Once the person you love is no longer able to continue their life, it is both good, honorable and the right thing to do when you gift someone else, who is dying, with a second chance. We all knew Jason and his kindness and felt very strongly that this is what he would have wanted us to do. His heart, kidneys and eyes were no longer of use to him, but helped five other people go on with their lives even though his was over. It was Jason's last gift to a world he had the greatest affection for.

MP Why should people consider being an organ donor?

KH There is a continuing need for organ donation. On average, 18 people die each day waiting for a life-saving organ. A new name is added to the national organ transplant

waiting list every 10 minutes. All anyone needs to do to be convinced that this is right, is to talk to a family whose loved one is waiting for an organ in order to survive.

MP In what other ways can people help the cause?

KH Make sure the people around you know your feelings on organ donation, so your loved ones can fulfill those wishes without any doubt. It's so hard for people to be thinking about organ donation for the first time when they are amidst an overwhelming tragedy. It's something that no one ever wants to be faced with, and if you make sure that all who care about you know your own wishes then you can spare them one more decision during an already very difficult time.

editorial@mediaplanet.com

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LISA T.

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† Median time to transplant for heart patients listed 1A between 7/1/2013 and 3/24/2014. Source: TIMS, Transplant Referral Management System. Physicians are members of the medical staff at one of Baylor Health Care System's subsidiary, community or affiliated medical centers and are neither employees nor agents of those medical centers, Baylor Health Care System or Baylor Scott & White Health. ©2014 Baylor Scott & White Health All rights reserved. ACHC_414_2014_Consumer_Heart_Transplant_AD

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