

Powerful Patient #6

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The Perfect Gift: Kidney Transplant

In October 2007, Edbassmaster, one of the comedy personalities of YouTube, donated a kidney to his sister. Many of his fans sent messages of support for him and his sister. On this program we meet with Ed and Maureen to talk about their experience.

In December 2007 there are 98,061 people on the transplant waiting list. In 2007, 10,847 living or deceased organ donors have given one or more organs to save the life of another person, or significantly improve their quality of life. 21,401 transplants have been performed.



Edbassmaster as Mr. Teste in "The Real Santa" at www.youtube.com

In this program you will hear one person's story of losing the last of her own kidney power following a series of surgeries to prevent kidney cancer from metastasizing. The eighth operation left her with no more functioning kidney. It cured her kidney cancer, but put her on dialysis.

The kidney is a pretty amazing organ. People with only 25% of one kidney can do well, and not even have to change their diet. So a person with two healthy kidneys has much more than necessary for good health – essentially, we are born with a backup just in case. We are used to thinking of the kidney as an organ that takes waste products out of the bloodstream, and makes urine which is then passed to the bladder for elimination. This is the lower part of the digestive process – we take in food and air, from which we derive all the goodness that fuels our bodies. The waste is carried away by kidney and bowel.

In fact, the kidney does this and more. Dialysis is only a crude approximation of this primary function of the kidney. Little by little we are understanding the other functions of the kidney, which dialysis does not do. While it's great that dialysis exists, the only way for this person to truly feel better is to have a new (used) kidney.

People in need of lung or liver transplant don't even have dialysis available to them – without a new lung or liver, they will die. Each year 10,000 people die while on the list, waiting for an organ.

Depending on the person's blood type, it can take 1-5 years on the transplant list before a donor can be found. As you will hear from Maureen, dialysis is not pleasant, especially for people with zero kidney power. Cadaver donors are people who have expressed their

willingness to give their kidney by signing up on their driving license, and who die in a way that the organ has not been damaged.

YOU can help – sign up on your driving license, and talk with your family and friends. You give away your old clothes when you no longer need them – why not also give the precious organs you no longer need to save a life, and help someone get well.

Remember too that not all transplants come from people who die. Even in your lifetime, you can give this incomparable gift – as Ed has done for Maureen. If you donate a piece of your liver, your liver will in fact grow back to its original size. If you donate a portion of your lung, you can save a life. If you are willing to consider it, go through the evaluation process and talk with the transplant team about your concerns. They will not allow a donor to do anything that will endanger the donor’s own health. “First do no harm” is the watchword in evaluating donors.

1) **Our Guests**

Edbassmaster lives in Philadelphia with his wife and two children. A standup comedian, he joined YouTube a year ago, and began making videos. He had just posted his 123rd video when we spoke with him. One of his videos, “Doggie Driving” will be shown on Fox TV this winter. You can view his videos at

<http://www.youtube.com/user/edbassmaster>

You can “subscribe” to his videos, and receive notification whenever there is a new one.

Some of the videos referenced or played as part of this program are:

Dog Drives Car!! <http://www.youtube.com/watch?v=Qp5DkqAxvAI>

Francis the Ex-Gangster <http://www.youtube.com/watch?v=Bwjd9g09SmQ>

Earl on the Dr Phil Show <http://www.youtube.com/watch?v=2A1fJzJuMV8>

Vinny Sings <http://www.youtube.com/watch?v=K0wnyPW0ubE>

Sanjaya...Rajeesh loves you <http://www.youtube.com/watch?v=hwMkICttQAE>

Tribute to Steve Irwin <http://www.youtube.com/watch?v=R1w91s1dBT0>

Keystone Cop <http://www.youtube.com/watch?v=6ulR88fJLIA>

Lisa Lavie, “Angel” in Full <http://www.youtube.com/watch?v=ijUHJyg6n04>

Oscar and Sir Richard on myfamilychannel

<http://www.youtube.com/watch?v=q6gyJCLBTUY>

Maureen, Ed’s sister, is 26 years old. She has been blind since the age of 17, and has undergone more than 20 surgeries. She lives in Philadelphia, where she has worked as a massage therapist.

Maureen, her mother and another brother, have a condition called von Hippel-Lindau (VHL). This is a tiny misspelling in one gene that normally suppresses tumor formation. This increases a person’s risk of certain tumors of the retina, brain, spinal cord, kidney, pancreas, and adrenal glands. Left untreated, the kidney and pancreatic tumors will grow and become full-blown cancers. To keep her from getting metastatic kidney cancer,

Maureen has undergone a series of eight “partial nephrectomies” – operations to remove the cancerous tumors before they could spread to other parts of the body.

Hers is a particularly aggressive case of VHL. Her own mother and brother have experienced fewer problems with VHL.

Maureen mentions having a tumor in her bladder. This was a pheochromocytoma, which occurred in her bladder, presenting some particular challenges in diagnosing and removing it, but she came through that episode safely.

She mentions having her eyes enucleated. Once the retina detaches, the eyeball is not getting sufficient nutrition and will begin to deteriorate. Eventually the pressure in the eyeball increases causing pain, and the eyeball itself may become unsightly. At this point, people often elect to have the eyeball removed, to take away the source of the pain. A prosthesis (false eye) is created to look just like the other eye, and moves naturally with the other eye, which brings the person back to a healthy appearance.

2) More about organ donation

Organ donors are badly needed. Won't you let your death possibly help another? Sign that organ donor card at the driving license bureau! And be sure to let your family and friends know that you want to do this, so there will be no doubts if and when it becomes time to make those ultimate decisions.

You can also make an organ donation during your lifetime.

If a loved one needs a new organ, please consider it seriously. It's a privilege to be an organ donor and make a dramatic difference in the life of someone you love. Even if you are not the right blood type, you might still be able to help. In some regions they accept “designated donations”. Joe wanted to give a kidney to his wife Sandy, but he was not the right blood type. With the help of their local organ donation center, they were able to organize a three-way donation – Joe's kidney went to the person at the top of the list in his blood type category, and Sandy received the next cadaver organ available that was a match for her. All three people are doing great.

3) More about von Hippel-Lindau

Von Hippel-Lindau (VHL) is a genetic cancer risk factor, raising the probability that you will get one or more tumors in your lifetime in one or more of the following areas of the body: retina, brain, spinal cord, kidney, pancreas, and adrenal glands.

Depending which tumors grow, the symptoms will vary widely. Diagnosing a new case of VHL is quite difficult. If a family knows that there is some level of risk, it is important to communicate that information to other family members, and use that information to protect yourself and others by finding issues early, and treating them appropriately.

With early detection and careful management, people with VHL are living full and happy lives. Delayed diagnosis or inappropriate treatment can result in significant disability or death.

For information about VHL, see <http://www.vhl.org>, and especially the Handbook at <http://www.vhl.org/handbook> For the publication on compiling a *Family Health Tree*, see <http://www.vhl.org/power>

4) More about pheochromocytoma

See <http://www.vhl.org/pheo>

5) More about rehabilitation services for the blind

Rehabilitation services for blind people are available in every state. If someone is losing their sight, they can obtain access to free audio library services (books are mailed to you) and coaching on doing the things you love to do with minor adaptations that make it possible to continue doing your favorite things.

The following site is helpful in locating such services:

<http://www.blind.net/rr000002.htm>

A guide dog can be wonderfully helpful if it fits your lifestyle. See http://en.wikipedia.org/wiki/Guide_dog for an overview and pointers to various guide dog training schools. Your local rehabilitation services can also refer you to the agency they use in your region.