



The clock is running. Make the most of today. Time waits for no man. Yesterday is history. Tomorrow is a mystery. Today is a gift. That's why it is called the present.

# HOPE CHEST NEWS

SPRING 2011

## Julia Bombeck Shares Her Journey To Transplant

### Believe - Hope - Breathe

Believe, Hope, Breathe. These words have become my motto for living with cystic fibrosis and my wait for a double lung transplant. Believe has been my peace and my strength. I believed that God would deliver the lungs to me at the perfect time and He did. I have

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much hope for a new life, for my family and for more organ donors. I never lost hope that the transplant would come before the disease robbed me of my life. I hoped that once I had my transplant, I would breathe like I've never

been able to breathe before. Most patients are diagnosed with Cystic Fibrosis when they are



Bruce, Megan, Julie & Jared

very young. In 1984, I was 20 years old when I was diagnosed and just starting my third year of college. The average lifespan of a "CF'er" was 19. The doctor told me I would probably live less than 10 years and I didn't like his predictions so I found the Cystic Fibrosis Center in Omaha, Nebraska for my medical care.

I began the routine of a CF'er and was now tied to percussion, nebulizer treatments and hospital stays along with the rigorous schedule of college. Within a month after I was diagnosed, I met the love of my life, my hus-

*(Continued on page 2)*

Our mission is to support and educate University of Minnesota Medical Center, Fairview patients and their families as they progress through the process of lung or heart / lung transplantation, and to promote public awareness of the needs of these patients.

band Bruce. We were married in August of 1986. I graduated from college in December, 1987 with a Bachelor's in Finance. We decided to have children knowing that my husband might have to be a single dad. In 1989, I gave birth to our first child, Megan and in 1991, our son Jared was born. Giving birth to two children was uncharted water at that time. For the next twenty six years, I did everything the doctors asked me to do. The disease was robbing me of my lung capacity and suffocating me. I was placed on the lung transplant list in Denver in 2008 and evaluated at University of Minnesota in February, 2010. On October 29, 2010, I was admitted to the University Hospital in Omaha. I started antibiotic i.v. therapy but I wasn't responding. My oxygen use had increased from four liters earlier in the week to twelve to fifteen units. On November 1<sup>st</sup>, Dr. Thompson in Omaha suggested I be transferred to a transplant center although no lungs were currently available. The medical staff didn't think I would be stable enough to take the air ambulance flight if we waited any longer. Bruce and I agreed that the move would be best. November 2<sup>nd</sup> I was flown from Omaha to the University of Minnesota. I chose the University of Minnesota as I was so impressed with the team at my evaluation. I remember very little of those days but my husband kept a wonderful journal on Caring Bridge and I have been able to be aware of just how sick I was. We were told that my left lung was not moving much, if any air and my right lung was very wheezy.

On November 7<sup>th</sup>, at about 11:50 a.m. my husband received a call that lungs were

available for me and that I would be scheduled for surgery tentatively at 6:00 p.m. My surgery began at 10:30 p.m. In addition to receiving new lungs, I had a hole in my heart that needed to be repaired. The doctors fixed the hole in my heart while waiting for the new lungs. My lung transplant began after midnight so my transplant date was November 8<sup>th</sup> 2010. The ventilator was removed on November 10<sup>th</sup> which was my forty-seventh birthday. I don't remember them removing the tube but I do remember birthday wishes and them asking me the date. I told them the date was November 10, 1963 and they kept correcting me that it was 2010! As a patient they ask your birth date so many times that I was "stuck" on that number and couldn't seem to get past it with the medication I was on! The rest of my story has been pretty much as I had hoped. My own expectations for myself exceed what the medical staff has requested of me. I have been getting stronger every week. I can't even describe in words how it feels to breathe - it is just the most wonderful gift from my donor. It is an amazing feeling to be able to lie down to go to sleep and not cough for an hour before I finally sleep. My day has been freed up from the six to eight hours of breathing treatments, vest and percussion that I was doing prior to transplant. I don't jump when the phone rings hoping that it's "the call". I know that I will continue to improve with exercise as opposed to declining as I was with my routine prior to transplant. I continue to believe, hope, breathe and pray that I won't have any problems with my transplant. I am thankful to all who have

had transplants before me and have helped educate the doctors and medical community in developing new medicines and procedures. I will be forever grateful to my donor;

he/she has already given me more days than I would have had without the transplant.

Julia (Julie) Bombeck

## Editorial and Presidential Ramblings

This is what happens when someone is filling 2 different jobs. You'll get both the editorial and the presidential perspective (both are probably worth what you're paying for them). On the editorial side; a big thank you to Julia Bombeck for taking the time to tell her story. Julia lives in Nebraska so coming to Minneapolis for the transplant was a major thing, not only for Julia, but her family. She is back home and doing well. Thanks again Julia.



I'm a transplanted (location and lung wise-sorry for the pun) Cheese Head so the Packer win

in the Super Bowl was awesome. The helmet was not far from where we live in a front yard. It took a lot of snow and hard work.

Planning work for the golf outing is in high gear (see the announcement further back). The committee has made 2 changes this year. The outing will be held at a different course, Gross National, and it will be on a Saturday instead of a week day.

The Hope Chest News annual meeting will be on June 20th. The election for officers and board members is done at this meeting so if there is someone out there who wants to get involved, this is a meeting you will want to attend.

Hope Chest News will be holding the 1st bake sale of the year on March 14th. Each year the sales (4 of them) have generated about \$3,000. The folks in the Twin Cities deserve a big thank you for all of the work that goes into buying inputs like sugar, butter etc., baking things and working at the bake sale. I think we're going to have to try and share the wealth and contact folks in the Twin Cities area that might be able to help out with baking and staffing the sales. I don't want this to turn into a scene reminiscent of school where you're sitting there thinking "Don't let him call on me because I didn't do my homework". As the Arizona senatorial candidate said "Man up"!! Help out here or your phone may be ringing.

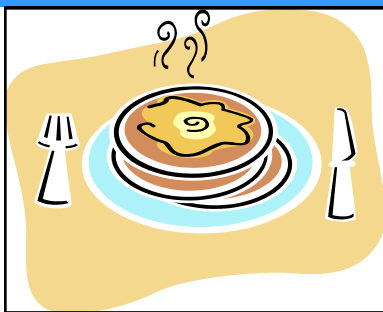
Finally, I hope that we're able to enjoy some nice spring weather. We have paid our penance this winter. Stay well.

*Ross Atkins*

## Transplant Anniversaries January to March

Matt	Bartocci	01/09/06	Bridget	Shaffer	02/18/06
Mary Lee	Carhill	01/30/08	Sonja	Sitzman	02/22/09
Marge	Engstrom	01/31/00	Barb	Tackaberry	02/07/02
Lester	Fuhrmann	01/04/07	Linda	Tollakson	02/17/09
Karen	Jacobson	01/12/07	Gary	Wulf	02/20/97
Dennis	Orlikowski	01/07/98	Shirley	Baumberger	03/09/06
Mary	Paquette	01/10/08	Brent	Bowen	03/23/90
Eva	Quirk	01/25/02	Ronald	Bowman	03/20/07
Stella	Regenneiter	01/27/95	Richard	Butschi	03/22/01
Jennifer	Rousseau	01/31/08	Grace	Charboneau	03/19/92
Gary	White	01/25/09	Gail	Deichert	03/19/01
Michael	Bluhm	02/01/03	Clay B.	DuVal	03/26/08
Noreen	Burke	02/21/95	Donald	Eastman	03/03/02
Rose	Dalager	02/05/98	Karen	Fisk	03/25/01
Brent	DeBoer	02/05/03	Brian	Frederick	03/14/05
Sharon	Durante	02/25/97	David	Goroski	03/13/98
Mae	Eastman	02/19/09	Peter	Kosberg	03/01/07
Mark	Gammon	02/19/99	Eugene	Kuhns	03/01/01
Maxine	Golombiecki	02/29/04	Sheila	Long	03/02/97
Shelle	Goodwin	02/18/08	Bob	Mathis	03/16/98
Ruth	Heinen	02/11/99	Leland	Nelson	03/16/99
Bobbie	Holmes	02/14/06	Timothy	Olby	03/02/07
DuWayne	Johnson	02/06/06	Greg	Runge	03/22/02
Ralph	Loftus	02/09/08	Diane	Sickels	03/01/03
Sue	Martin	02/20/07	Sharol	Sturart	03/25/99
Donna	Meegan	02/17/07	Cathie L.	Vaara	03/23/05
Linda	Meyer	02/14/02	Tom	Vanderpool	03/21/05
Hannah Joy	Olson	02/18/06	Michael	Wenner	03/31/07
Mary Fern	Olson	02/20/07			

## Save The Date



Sunday, April 17th is the pancake breakfast at the Litchfield Eagles Club. Hal Wenaas coordinates this event

for the benefit of Hope Chest News. The

pancakes are great and you always get plenty to eat. They crank up those griddles pretty early in the morning so it's unlikely that you'll get there and find the lights out. Food is served through lunch. Gas is going up but it's worth the trip to Litchfield for the food and a good portion of the proceeds go for patient support with Hope Chest News.

## Upcoming Events

U of M support group meeting is on Mondays at 11 A. M. in the Lillehei Conference Room at U of M Fairview Hospital. There is no meeting on the 1st Monday of each month.

Monthly Evening Support Group is held at 7 P. M. on the 1st Monday of each month in the Lillehei Conference Room. Caregivers Support Group is held on the 1st Monday of each month at 6 P. M. in the Lillehei Conference Room at U of M Fairview.

Sioux Falls Support Group is on the 3rd Thursday of each month at 7 P. M. The meetings are held in the Cancer Institute at McKennan Hospital in Sioux Falls. For more information contact June Schneider at 605-339-3067

Monthly Meeting of the Hope Chest News Board of Directors on March 21, April 18 and May 16 at 12:30 P. M. in the conference room of the Bridges cafeteria at U of M Fairview.

## Donations And Memorials

### In Memory of Dan Clay

William & Lois Kelly

### In Memory of Sue Saffel

Bruce Saffel

Kathleen Greising

Mathew & Alissa O'Hara

Hinda Litman

### In Memory of Judy Murphy

Charles Ravine

### In Memory of Eileen Ronning

Wayne Anderson

Judy Vermeulen

Kathleen Greising

### Donations

John & Karen Ramerth

Michael Ramerth

Kathy Gosgrove

Sandy & Mike Sazama

Christine Bue

Tom Bodmer

Tammy Mavaro

## U of M Transplant Program Honored

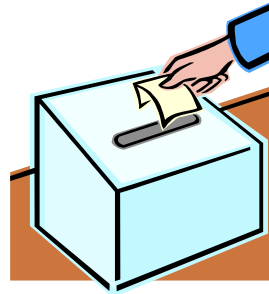
HealthGrades, the leading independent ratings organization in the US, named the University of Minnesota lung transplant program as one of the best in the country. The Heart Grades Lung Transplant Excellence Award was announced recently. There were 53 hospitals evaluated. The evaluation examines

survival rate and the chances of receiving a lung. The University program was ranked number three of the fifty three that were evaluated. We're fortunate to have access to the program. The information on the rankings is available at HealthGrades.com.



## Annual Meeting of Hope Chest News

The annual meeting of Hope Chest News will be held on June 20th. The meeting will begin at 12:30 pm in the Bridges Conference room. Election of officers and board members will take place. Remember, Hope Chest



News is your group. If you would like to become involved or have something you'd like to have considered, please attend the meeting.

## Remembering Those Gone

Fortunately, we didn't lose any transplant friends since the last newsletter. Remember, if you lose a loved one and wish to have the information in the newsletter, you have

to let us know. Email can be sent to [agsector@gmail.com](mailto:agsector@gmail.com). Because of the large geographical area covered by the newsletter, we often have no way of knowing of your loss.

## Recent Transplants

January 14, 2001—J. Tom Fuller received a single lung.

January 20, 2001—Patricia Klang received a single lung.

October 4, 2010—Ron Staples, a double lung.

October 10, 2010—Richard Locket, a double lung.

November 8, 2010—Julia Bombeck, a double lung.

December 21, 2010—Jamie Hammer, a double lung.

March 2, 2011—Cynthia Gingras, a double lung.

There were also 3 double and 2 single lung transplants completed between October and January .

The names of some of the transplant recipients aren't included because of HIPPA rules. Marget Schmidtke needs patient permission to release their name. Contact her for your transplant information then send it to the mailing address or E-Mail it to [hopechest-news@aol.com](mailto:hopechest-news@aol.com). If any of the transplant recipients this year would like to have their name included in the newsletter, let us know. Also, if you let us know the date of your transplant and your transplant number, we can make a button for you.

## Transplant Morsels—Bits Of Information

### ***Study Indicates An Increase In Lung Availability For Transplant***

An abstract from the December 15, 2010 is-

sue of the *Journal of the American Medical Association* details a study from 12 European intensive care units that led to a much higher

percentage of lungs that would meet the requirements needed for transplantation. Ventilator pressure in 1/2 of the possible donors was kept at the conventional level of 10-12 ml/kg of predicted body weight and 1/2 were kept at 6-8 ml/kg (protective strategy) . 54% met donor eligibility criteria using accepted ventilator strategy after the 6 hour observa-

tion period. 95% of potential donors met donor eligibility using the protective strategy. The conclusion of the study was that the use of the protective strategy in potential lung donors increased the number of eligible and harvested lungs compared to a conventional strategy. **Source: Journal of the American Medical Association**

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### ***Growing Replacement Organs***

The Holy Grail of organ and tissue replacement is growing replacement tissue that matches the recipient perfectly. There wouldn't be rejection issues or organ shortages. **Nova Science** has put out a fascinating piece

about growing your own replacement parts. It details how vessels and ear cartilage are being grown now. The future holds the possible ability to grow more complex organs such as kidneys, hearts and lungs. If you have access to the Internet, you can view it at <http://video.pbs.org/video/1754537562>

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### ***Music May Help Prevent Falls?***

A very small study from the University Hospitals and Faculty of Medicine of Geneva showed that listening to music while exercising might help older people with their balance and cut the risk of falling. The research

found that listening to music while exercising lowered the number of falls and improved the "gait and balance" The report on the small study appeared in the ***Archives of Internal Medicine***. The researchers felt that fall prevention in senior centers might be improved.

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### ***Pulmonary Fibrosis Foundation (PFF) Forms Support Group in Twin Cities***

The first meeting of a pulmonary fibrosis support group was held on March 8th in Plymouth, MN with 18 attendees, The group's purpose is to provide information and support for patients and family members who have the disease affecting their life. The next meeting is tentatively scheduled for April 19th. The meeting will be held at 11140 Highway 55, Suite D in Plymouth. The group is seeking a site to hold future meetings because the number of folks attending has al-

ready strained the current site. Melinda (Mel) Bors, Care Coordinator with the Interstitial Lung Disease Clinic at the University of Minnesota is acting as the temporary group coordinator.



If you would like more information about the group, she can be reached by

phone at 612-625-0470. Her email is [mbors10@umphysicians.umn.edu](mailto:mbors10@umphysicians.umn.edu).

## **Cystic Fibrosis Foundation Announces Drug Trial Success**

The oral drug VX-770 was tested in a Phase 3 trial and shows marked improvement in CF patients. The drug targets the defective protein that causes CF. "Patients who took the drug showed marked improvements in a number of key measures of the disease, in-

cluding improved lung function, fewer pulmonary exacerbations, patient related reductions in respiratory symptoms and weight gain." VX-770 is being developed by Vertex Pharmaceuticals. The company plans to submit an application to the Food and Drug Administration for possible approval sometime in 2012.

## **Pulmonary Fibrosis Foundation (PFF) to Host IPF Summit**

PFF recently announced that it will host a summit on IPF in Chicago December 1-3. Friday, December 2nd will be a session for Physicians, Registered Nurses and Researchers. Saturday, December 3rd will have full day sessions for medical professionals and there

will be sessions all day for patients and caregivers as well. More information about the Summit can be found on the Internet at <http://www.ipfsummit.org/index.php>. There is no charge for patients and caregivers.



## **COPD Foundation to Host Continuing Medical Education Conference**

A continuing medical education conference will be held in November, 2011 in Washing

ton, DC. The conference will run for 2 days. The conference is for medical professionals. For more information, send your request to [copd7usa@copdfoundation.org](mailto:copd7usa@copdfoundation.org)

Mark your calendar for the 5<sup>th</sup> Annual Marie Anderson Memorial Golf Tournament, a fundraiser for the Hope Chest News lung transplant non-profit organization. This year the event will be held Saturday, July 30<sup>th</sup> at:

Gross National Golf Course  
2201 Saint Anthony Blvd  
Minneapolis, MN 55418-3120



Registration is \$110.00 if paid by July 15<sup>th</sup> 2011, \$120.00 if paid after that date. For more information and a registration form, go to the HCN web site at [www.hopechestnews.org/Golf.html](http://www.hopechestnews.org/Golf.html) or send an E-Mail to [hopechestnews@aol.com](mailto:hopechestnews@aol.com) or contact one of the tournament coordinators: Hal Wenaas 320 221-0682 – [mjhal@hotmail.com](mailto:mjhal@hotmail.com)  
Gary Broberg 651 456-0340 – [broberg2281@comcast.net](mailto:broberg2281@comcast.net)  
Ed Aubitz 952 457-8281 – [eca123@comcast.net](mailto:eca123@comcast.net)  
Barb Peterson 952 431-8442 – [petersonkip@aol.com](mailto:petersonkip@aol.com)





## Consumer Reports Best Buy Drugs

**Consumer Reports** maintains a website that lets users garner information on drugs. The interactive site lets you learn everything from off label drug use and prescribing to money saving guides.

Many transplant patients use the services of the Fairview Specialty Pharmacy but this site offers a number of different topics that are very useful and informative. The site can be accessed at <http://www.consumerreports.org/health/best-buy-drugs/index.htm?CMP=OTC-BBDHPA5>

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## Arizona Cuts Medicaid Coverage For Transplantation

The State of Arizona has eliminated coverage for transplants. In a cost saving move, the state has cut funding for certain transplants of the heart, liver, lung, pancreas and bone marrow. Transplant centers in the state are advocating a special session to restore funding. While Arizona is quite a distance from the mid-west, budget deficits are a problem in almost every state in the US. Transplant recipients and those waiting

need to monitor this very closely. The cut in funding in Arizona could mean a death sentence for those waiting for a transplant and



could happen in other states. This is a dangerous trend for those needing a

transplant.

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## European Union (EU) Approves Drug For Idiopathic Pulmonary Fibrosis

The EU recently approved the sale of Esbriet (pirfenidone) for the treatment of IPF. The drug was developed by Intermune. The drug has shown some effectiveness in treat-

ing mild to moderate IPF. The drug is available to patients in Japan and now in the EU. The FDA rejected the application of the company for the drug's approval in the US and has asked for another trial before it could be possibly sold in this country.



## Alpha-1 Association Presentation On Lung Allocation

Martin R. Zamora, M.D. explains how those awaiting transplant can learn how the program works. Lung allocation score, blood type, geo-

graphical distance between candidates, the hospital where the donor is located and more. There is a lot of information that anyone awaiting a transplant will find helpful. The presentation can be found online in the January, 2011 issue of **Community Currents**, the Alpha-1 e-newsletter. If you are waiting, you will find this is a good tool to help understand the process of organ allocation.

## TSA Requirements For Oxygen While Flying

Sorry for the smaller font and hope your eyes don't glaze over; this is a government written bit of information.

Supplemental personal medical oxygen and other respiratory-related equipment and devices (e.g. nebulizer, respirator) are permitted through the screening checkpoint once they have undergone screening.

Any respiratory equipment that cannot be cleared during the inspection process will not be permitted beyond the screening checkpoint.

Persons connected to oxygen:

- Inform the Security Officer if your oxygen supply or other respiratory-related equipment cannot be safely disconnected.
- Only you can disconnect yourself to allow for your oxygen canister/system to be X-rayed.
- Check with your Doctor prior to coming to the checkpoint to ensure disconnection can be done safely.
- If your Doctor has indicated that you cannot be disconnected or if you are concerned, ask the Security Officer for an alternate inspection process while you remain connected to your oxygen source.
- Infants will remain connected to their apnea monitors throughout the screening process. Apnea monitors will be screened while remaining connected to the infant.
- Oxygen equipment will either undergo X-ray screening (only disconnected oxygen equipment) or physical inspection, and explosive trace detection inspection.



Oxygen suppliers or persons carrying oxygen supply:

- An oxygen supplier or personal assistant may accompany you to the gate or meet you at the gate once they have obtained a valid gate pass from the appropriate aircraft operator.
- Persons carrying his/her supply must have a valid boarding pass or valid gate pass to proceed through the security checkpoint.

- Oxygen being carried by the supplier or person will either undergo X-ray screening and explosive trace detection sampling.

### Oxygen and Arrangements

Passengers are responsible for making the arrangements with:

The airlines) for supplemental Oxygen onboard the aircraft. Local providers for oxygen use during any layover stops) and at the final destination.

- The airline, friends, relatives or a local supplier for removal of the canister from the originating airport's gate area immediately after you leave the gate area to board the aircraft.

You must make similar arrangements for your return trip. Please, check the procedures outlined below for details. More information on airline accommodations for oxygen users can be found at the National Home Oxygen Patient's Association [web site](#). You can also download the "[Airline Travel With Oxygen](#)" brochure. This publication provides valuable information on traveling with oxygen, including airlines that do and do not provide in-flight supplemental oxygen.

### When You Make Your Reservation:

*Arranging for Supplemental Oxygen (O2) Aboard the Aircraft*

- Neither the Air Carrier Access Act nor the Americans with Disabilities Act require airlines to provide oxygen service. Consequently, airline policies, procedures and services on accommodating passengers who use supplemental oxygen vary widely.
- Notify the carrier when you make your reservation that you will need to use supplemental oxygen aboard the aircraft(s).
- Ask about the airline's policies on the use of supplemental O<sub>2</sub> onboard. Federal regulations prohibit airlines from allowing passengers to bring their own oxygen canisters aboard to use during the flight. Passengers who use oxygen canisters must purchase canisters from the airline for use during the flight. However, some airlines do permit passengers to bring aboard oxygen concentrators, which do not contain oxygen, and use them during the flight. Policies vary from carrier to carrier, so be sure to check with your airline well in advance.
- Keep in mind that not all airlines offer supplemental oxygen service, or may not offer it aboard



all their aircraft. Inquire whether: 1) the airline provides oxygen service, 2) it is available on the flights you wish to take, and 3) you must provide a doctor's letter, or permit them to contact your doctor di-

rectly to verify your medical need.

*Arranging for Supplemental Oxygen during Layovers or at Your Destination*

- Notify the carrier(s) you are traveling with that you will need oxygen at the airport(s). Let them

know that your O<sup>2</sup> supplier will be meeting you at the gate with an O<sup>2</sup> canister.

- Ask about their policy for allowing O<sup>2</sup> suppliers to meet you at the layover airports and/or at your destination gate.
- Contact your O<sup>2</sup> supplier and request that they make arrangements for your O<sup>2</sup> at the city or cities you'll require. The supplier will need to know the airline(s) you'll be using, departure and arrival dates and time, departure and arrival gates, flight number(s), arrival time(s), and the equipment you will need. Make all these arrangements as soon as possible.
- If a representative from the oxygen-providing company is going to meet your flight with an O<sup>2</sup> canister, arrange for your flight(s) to arrive during the supplier's normal business hours, if possible. Also, have a local phone number and a contact person in the event of any unforeseen situation (s), such as if their representative is not at the arrival gate when you get there

### Hope Chest News Board of Directors And Officers

The Board members and their duties and contact information are as follows:

Ross House, President	763-593-9745
Candace Sprout, Vice Pres.	612-338-3419
Kathy Greising, Secretary	763-383-2255
Ed Aubitz, Treasurer	952-457-8281
Gary Broberg, Director	651-456-0340
Vern Jackson, Director	651-696-2962

Hinda Litman, Director	952-935-1687
Ralph Loftus, Director	763-428-3531
Sue Martin, Director	952-432-4231
Barb Peterson, Director	952-431-8442
Judy Vermeulen, Director	952-445-2497
Ellen Varney, Director & Communications	906-524-7845

Contact any of the Board members with ideas, concerns or questions.

### Who Should I Contact For

Address or E-Mail Change or Heart/Lung Status Change: Candace Sprout 612 338-3419 or [mandccando@earthlink.net](mailto:mandccando@earthlink.net)

In the Hospital: Any Board member  
Financial Assistance or obtain your transplant number: Marget Schmidtke, Thoracic

Transplant Social Worker at 612-273-5796 or 1-800-478-5864

Mentorship Program or Newsletter : Ross House 763-593-9745 or [agsector@gmail.com](mailto:agsector@gmail.com)

Hope Chest News

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## For The Computer Challenged Older Group

This was recently forwarded to me:

As we silver surfers know, sometimes we have trouble with our computers. I had a problem yesterday , so I called Eric, the 11 year old next door. His bedroom looks like Mission Control, and asked him to come over. Eric clicked a couple of buttons and solved the problem. As he was walking away, I called after him, ‘So what was wrong’? He replied “ID ten T error”. I didn’t want to appear stupid, but nonetheless inquired “An ID ten T error”? What’s that in case I need to fix it again?

Eric grinned. “Haven’t you every heard of an ID ten T error before? “No” I replied. “Write it down”, he said and I think you’ll figure it out.

So I wrote it down:

**ID10T**

I used to like Eric, the little b\*\*\*!\*\*\*@@!!