



Hope Chest News

PATIENT NEWSLETTER

April - June 2008

The information provided in this newsletter is for educational purposes only, and it is not nor implied to be a substitute for professional medical advice. Always consult your own physician or healthcare provider with any questions you may have regarding a medical condition.

Mission Statement

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

Renewing Spirit: A Gathering of Caregivers

If you are, or have been a caregiver of a lung or heart transplant patient, this full day conference is being held just for you!

Renewing Spirit: A Gathering of Caregivers will be held on Saturday, September 13, 2008. This is a conference sponsored by University of Minnesota Medical Center, Fairview. There will be a special keynote speaker, plenary sessions on relevant topics, wonderful food, a beautiful setting, great music and lots of time to spend with both old friends and new. It truly will be a wonderful way to renew your spirit!

This conference will be held at the beautiful Dolce Oakridge Conference Center in Chaska. The center is situated on a lake with lots of walking trails to enjoy. They are known for their wonderful food and great hospitality. Feel free to check out all of the amenities available at www.oakridge.dolce.com.

This event was originally scheduled for April 2008 but had to be changed because of speaker conflicts. More information and registration information will be sent this summer. Be sure and mark your calendars now so you do not miss out on this event.

If you have questions or would like more information about the conference, please call Barb Peterson at 952-431-8442 or E-Mail her at petersonkip@aol.com

2008 Transplants

As of June 21 there have been 11 Lung transplants and 12 Heart transplants.

Lung Transplants				Heart Transplants		
Name	Type	#	Date	Name	#	Date
	D/ L	203	01/ 05/ 08		639	01/ 07/ 08
Mary Paquette	D/ L	204	01/ 10/ 08		640	01/ 12/ 08
	S/ L	358	01/ 30/ 08		641	01/ 15/ 08
Jennifer Rousseau	D/ L	205	01/ 31/ 08		642	01/ 30/ 08
Ralph Loftus	D/ L	206	02/ 09/ 08		643	02/ 08/ 08
Shelle Goodwin	D/ L	207	02/ 18/ 08		644	02/ 16/ 08
	S/ L	359	03/ 26/ 08		645	03/ 05/ 08
	S/ L	360	04/ 02/ 08		646	04/ 08/ 08
Viola Poeschl	S/ L	361	05/ 02/ 08		647	04/ 15/ 08
	S/ L	362	05/ 02/ 08		648	04/ 30/ 08
	S/ L	363	06/ 05/ 08		649	05/ 21/ 08
					650	05/ 29/ 08

Due to HIPPA rules, Marget Schmidtke needs permission from patients to release their name, transplant number and date. Contact her for your transplant number. If any of the people transplanted this year would like to have their name printed in the newsletter, please E-Mail HopeChestNews@aol.com or you can call Ed Aubitz at 952-457-8281. If you let us know the date of your transplant and your transplant number, we can also make a button for you.



Anniversaries

April

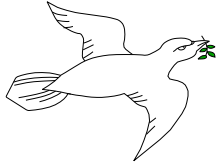
321	Richard Berg	SL	04/ 08/ 06	28	Doug Markus	HL	04/ 08/ 93
56	Thouy Bouanien	DL	04/ 12/ 97		Judy Ogden	DL	04/ 01/ 05
156	Ross Bourgeois	DL	04/ 04/ 05		Shawna Ristau	DL	04/ 02/ 02
320	Rhonda Cannon	SL	04/ 06/ 06	51	Leon Roder	SL	04/ 24/ 93
253	Mary Davis	SL	04/ 16/ 03		Francis Steinke	DL	04/ 13/ 02
	Tom Deimerly	DL	04/ 15/ 04	49	Carol Stimmel	SL	04/ 23/ 93
45	Barry Dyer	DL	04/ 01/ 96		David Talbot, Jr.	SL	04/ 08/ 06
189	Thomas Goldspring	SL	04/ 11/ 00	112	M. Douglas Weasley	SL	04/ 01/ 96
288	Daisy Hoffman	SL	04/ 29/ 05	179	Harriette Wock	DL	04/ 11/ 06
287	Debbie Kietz	SL	04/ 03/ 05				
254	Andy Kronholm	SL	04/ 16/ 03				
85	Tracy Macius	DL	04/ 05/ 99				

May

134	Jim Audsley	DL	05/23/03	157	JoAnn Miller	DL	05/01/05
289	Thomas Bodmer	SL	05/31/05	107	Raphael Moreno	DL	05/04/01
	Kathleen Edmunds	SL	05/02/04	149	Elaine Nelson	SL	05/12/98
290	Darrell Ehrike, Sr.	SL	05/31/05	256	Karen Ness	SL	05/15/03
87	Kathryn Foss	DL	05/22/99	324	Mike Olson	SL	05/19/06
74	Judy Gratton	SL	05/18/94	166	Gene T. Phillips	SL	05/23/99
261	Bill Guthrie	SL	05/30/03	20	Anna Fiet	HL	05/24/90
39	Eugene Hrbek	SL	05/28/92	360	Viola Poeschl	SI	05/02/08
58	Greg Hules	DL	05/25/97		Darla Querry	DL	05/16/02
1	Ken Jones	HL	05/01/86	4	Pam Reinken	DL	05/10/91
75	Kathie Justice	DL	05/25/98	145	Susan Saffel	DL	05/18/04
275	Fran Kaye	H	05/26/93	133	Gene Schrunk	DL	05/22/03
77	Carla Landreth	SL	05/21/94	19	Judy Spray	SL	05/06/91
	Wanda A. Lisk	SL	05/05/01		Daniel Tix	DL	05/09/04
24	John Marino	DL	05/23/94	86	Vincent Voelz	DL	05/14/99
236	Ronald Martinson	SL	05/27/02	326	Lonny Walker	SL	05/23/06
90	Fredrick Meyer	SL	05/10/95	274	Ellen Weinand	SL	05/27/04

June

181	Jennifer Beitz	DL	06/25/06	78	Phillip Kraskey	SL	06/12/94
327	Todd Cram	SL	06/22/06	346	Worth Littlejohn	SL	06/02/07
94	Margert Doyle	DL	06/19/00	22	Larry Luttrell	SL	06/07/91
293	Leslie Fallstrom	SL	06/25/05	32	Robert Miller	HL	06/03/94
191	Ann Fuhr	SL	06/14/00	76	Robert Miller	DL	06/09/98
47	Sandra Heim	DL	06/23/96		Trudy Ras	SL	06/25/04
107	Barbara Hinzman	SL	06/17/89	93	Jeannine Santolizer	DL	06/19/00
39	Russell Hong	HL	06/21/97	31	Christine Theisen	HL	06/02/94
347	Vern Jackson	SL	06/20/07	46	Shawna Waulk	DL	06/19/96
133	Gail Jobe	SL	06/21/97	108	Elaine Werlinger	DL	06/08/01
25	Sandra Johnson	DL	06/21/94	95	James West, PhD	SL	06/18/95
	Larry Kershaw		06/26/05				



***In memory of loved ones
and donors please remember
them in your prayers***

We have lost more of our lung buddies:

Bonnie Bieber	s/l	transplanted 11/29/99	Passed away 10/19/07
Larry McKeever	s/l	transplanted 08/03/00	Passed away 02/25/08
Jeanne Peterson		waiting	Passed away 03/14/08
Nancy Thorson	s/l	transplanted 08/30/01	Passed away 04/05/08

Our prayers go out to their families and for any others who have passed away that we are not aware of.

Memorials

In Memory of Cynthia A. Ales Jo Ann & Michael Wroblewski	In Memory of Cynthia A. Ales Hinda Litman
In Memory of Carole Auer Leslie Auer	In Memory of Charlie Gauthier Beverly Gauthier
In Memory of Bill Greising Elizabeth House	In Memory of Pamela Hodek Gordon Olson
In Memory of Ricky Hauer Elizabeth House	In Memory of Larry McKeever Sharon McKeever
In Memory of Larry McKeever John & Susan Crabb	In Memory of Larry McKeever June Goettsche
In memory of all departed lung buddies Andy and Connie Kronholm	

Donations

Thank you to the following individual for her generous donation

Darlene Gieser	
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A note from Kathleen Edmunds

Hope Chest News received the following E-Mail from Kathleen Edmunds. We appreciate all communication from patients and caregivers. Thanks for taking the time to keep us up-to-date on your condition Kathleen. We wish you success in your drug therapy.

I am elated to hear from you all. I have just had my four-year anniversary from my single lung transplant at Cleveland Clinic (May 2004). I was first evaluated at Fairview, but was rapidly declining and needed to move to a center that would reach me sooner. I have been doing great and have gone back to work full time at a college in Cincinnati, Ohio. In December 2007, I found out I am in chronic rejection (not acute which would have a whole lot better) (my capacity is declining somewhat, but I still feel pretty good unless I start walking distances or fast, or try lifting and carrying objects). On 16 June, I am starting an experimental drug that has already gone through the initial FDA trials, but they still need a bit more study info. It is inhaled cyclosporine using a special nebulizer. I am told the side effects are the usual (as with Prograf and Cellcept) except that I may have a sore throat. I have to be in clinic each of the first five days it is administered, so I must travel from my home in Kentucky and stay in Cleveland, Ohio for the week. That is no biggie! I did get RSV in the winter (I had it two years ago too). I had to be hospitalized for five days and had the robo-virus isolated treatment. But hey, I'm doing great and my quality of life is wonderful right now. I am not on any oxygen at this point. I'm going to keep working and enjoying every beautiful day the good Lord is giving me. I KNOW I am here for a reason and I'm going to do my best to do my part!!!

I think of you all at Fairview often. I am very envious of your support group. I do not have anything like that through Cleveland. But I cannot complain about anything. You all keep up the good work. I enjoy receiving the newsletter so much and rejoice in each and every anniversary!

Kathleen Edmunds

Larry McKeever

Hope Chest News learned of Larry McKeever's passing on February 25, 2008 which was a little too late to include the announcement in the January – March issue of the Newsletter. His announcement is in this issue. His wife, Sharon, sent the following note to Hope Chest News. We all send our best wishes to Sharon and her family and thank her for this gracious note.

Dear Friends,

I received the Hope Chest News today, The first thing I looked for was Larry's name (Ed Note: Larry's name was not in that issue, see above).

We thank you for the kindness and consideration shown to me and Larry the past 7 years. It has all went way too fast.

Larry was a fighter, even the last three weeks.

I'm not sure I will ever be back to the University.

I do want to continue receiving the Newsletter. It will keep me connected to your program.

Thank you again.

Feel free to print the poem Megan wrote. Larry would have loved it.

Sincerely,

Sharon McKeever

Mitch, Tom, Doyle & Families

The note from Sharon also included the following touching poem from their granddaughter Megan. It was included in the brochure distributed at Larry's funeral with a picture of Larry and Megan. Thank you for sharing this with all of us Megan.

I haven't seen you in awhile
I hope I do for Christmas
You are sick again,
your body is slowly giving up on you
I look at you,
and you look back
with your sad droopy eyes.
I see all the pain and hurt
rush slowly through you.

Everyone says you'll be okay.
The doctors aren't so sure.
People tell me they know how it feels,
but they don't.
This is the hardest thing
I've been through in my life.
It just gets harder every day
not knowing how you are,
or how it will end up.
You've been through a lot,
since I was young.
You're constantly sick,
and you can barely breathe.
No one knows the pain you're in.
No one knows what you've gone through
because I decide to keep it to myself
Every time I think about it,
I want to cry.
I just wish it hadn't happened to you.
I don't want you to hurt anymore,
But nothing can stop that,
and that makes things worse

Grandma's having a hard time
trying to stay strong
and think positive.
Last time I saw her,
we both held each other tight,
crying on each others arms.
We were so scared of losing you,
and Grandma can't live without you.
She's constantly worrying about you,
or taking care of you

I still need the person I visit with,
the person I play cards with,
and eat ice cream with.
The guy who tells me,
that I'm too beautiful to wear makeup
The one I watch movies with,
when no one else is home.
I can't lose this person,
especially what we've been through.
I know that someone won't be around
when I get married,
Or have a baby.
But he's a fighter
and I love him so much.

He is my grandpa.

Thank You

A special thanks to all those who have donated to the Hope Chest News through memorials, honorariums or personal donations.

Any donations made to Hope Chest News will be used to either defray the costs of producing and mailing the newsletter or will be used to provide financial assistance to other FUMC heart/lung transplant patients and waiters. Proceeds from the sale of the cookbook and other items will also be used in this manner. Hope Chest News is a 501(c)(3) charitable organization and all donations are tax deductible. Please keep us in mind when you are making Honorariums, Memorials, or wish to make a tax deductible charitable donation.

All donations should be made out to Hope Chest News and be mailed to: Judy Vermeulen, 796 Regent Drive, Shakopee, MN 55379-8261

Newsletter Topics

- The Newsletter is produced on a quarterly basis.
- The Newsletter is also available online at www.hopechestnews.org. Click on the **Newsletter** tab on the left hand side of the page. Once there, you can view the newsletter or download a copy to your PC. We will provide E-Mail notification to you when the latest copy is available online. To request this service please send an E-Mail to hopechestnews@aol.com
- If you would like to share a personal story about your transplant experience, if you have questions or information you would like to share with other lung or heart transplant patients, please contact Ed Aubitz by calling 952-457-8281 or via E-Mail to hopechestnews@aol.com.
- If you no longer wish to receive the Hope Chest News please initial and date the following statement:

I do not wish to receive the Hope Chest News newsletter _____

Name: _____

Mail this page to:

Hope Chest News
C/O Ed Aubitz
161 East 105th Street Circle
Bloomington, MN 55420
* * * * *

Exercise Planning

A hint about when its OK to exercise. If you add the temperature and the humidity percentage and they are near or above 150, you should not do outdoor activities: e.g. if the temperature is 73 degrees and the humidity is 77% totaling those makes 150. It is not a good day for outdoor respiratory exertion.

This advice came from two respiratory therapist at a COPD information day.

News from the HCN Board of Directors

Kip Peterson, President (3)	952-431-8442	PetersonKip@aol.com
Ed Aubitz, Vice President (2)	952-457-8281	eca123@comcast.net
Judy Vermeulen, Treasurer (1)	952-445-2497	javfpv@aol.com
Kathy Greising, Secretary (2)	651-738-2954	kjgreising@aol.com
Julie Caron, Corresponding Secretary (3)		julicaron@gmail.com
Ross Bourgeois, Director (2)	763-522-6053	marross2537@comcast.net
Brenda Daml, Director (1)	763-753-4169	damltruck@msn.com
Ramona Foore, Director (3)	952-431-2884	rfoore@charter.net
Philip Gracia, Director (3)	651-293-0718	pgracia@inbox.com
Hinda Litman, Director (1)	952-935-1687	hlitman@hotmail.com
Elliot Sovell, Director (1)	507-694-1433	
Eileen Vierow, Director (2)	651-483-3146	eileenV10@hotmail.com
Harriette Wock, Director (3)	651-439-1808	Hmw1808@aol.com

President's Review

As winter has finally left us and we have jumped past spring into summer it's nice to have warmer weather once again. It felt like winter was never going to end.

So far this year there have been fewer heart or lung transplants done. We all continue to hope that these numbers will improve and more people will be given the gift of life. While awareness about organ donation is at an all time high, we still have not been able to decrease the numbers on waiting lists. I think it is important that we all do our part by continuing to promote organ and tissue donation.

Our major fundraisers this year are our two golf tournaments coming up this summer. The golf committee is working tirelessly organizing these tournaments so they will each be a success. The Larry Daml Hope Chest News Tournament has been changed to June 23rd due to scheduling conflicts. The Marie Anderson Tournament will be held on Monday July 28th.

Hope each and every one of you has a great, fun summer and stay healthy with no bumps in the road.

Kip

Treasurer's Report

Just wanted to let you know we are staying on Budget as I shared with you in the last newsletter.

We did receive a Grant from The Auxiliary at the U of M Hospital, Fairview in the amount of \$3,000.00 and will be using this in our continuing commitment to help our patients.

The fundraising from the 2nd. Annual Marie Anderson Golf Scramble is well on its way. We have raffle tickets available, for 1st. prize \$500.00, 2nd. prize \$300.00 and 3rd. prize \$100.00 (please contact board members to purchase tickets.). We have received a major sponsorship of \$1000 from Roche Pharmaceuticals. Others are still out but we expect to receive at least one more major sponsor.

We are receiving golfer registrations daily in the mail and are hopeful that we can fill the field of 144 golfers.

The next Newsletter I will have a complete report from our Annual Meeting.

If you have questions regarding the financial status of Hope Chest News you may contact me at. javfpv@aol.com or call me at 952-445-2497.

Sincerely

Judy Vermeulen

* * * * *

We don't want to miss you...

Marget has short-term parking passes for the group meetings. So come to group and if you need one just ask Marget. We don't want anyone to stay away from meetings because of financial concerns.

* * * * *

Important Numbers:

The following chart will help if you need assistance in one of the listed areas.

Purpose	Who to Contact	Phone Number	E-Mail Address
Address or E-Mail Change	Ed Aubitz	952-457-8281	eca123@comcast.net
In the Hospital	Any Board member	See list elsewhere	hopechestnews@aol.com
Financial Assistance	Marget Schmidtke, Thoracic Transplant Social Worker	612-273-5796 or 1-800-478-5864	
Heart\Lung Status Change	Ed Aubitz	952-457-8281	hopechestnews@aol.com
Mentorship Program	Eileen Vierow	651-483-3146	eileenv10@hotmail.com
Obtain your Transplant Number	Marget Schmidtke	612-273-5796 or 1-800-478-5864	
Heart Buttons	Ed Aubitz	952-457-8281	eca123@comcast.net

Hope Chest News Annual Meeting

The annual meeting of Hope Chest News will be held at 12:30PM on Monday, July 21, 2008 in the Bridges Conference Room. The 'Bridges' is located on the 8th floor of the Fairview University hospital. All members are permitted and encouraged to attend this important meeting.

Hope Chest News is governed by a 13 member Board of Directors. Four directors terms will expire in July and need to be filled; Judy Vermeulen, Brenda Daml, Hinda Litman and Eliot Sovell. A committee was named to recruit people to put on the ballot for this years election to fill the seats being vacated. Those who have agreed to be on the ballot are:

Judy Vermeulen _____ Ralph Loftus _____

Todd Gram _____ Vern Jackson _____

Mary Paquette _____ Hinda Litman _____

Brenda Daml _____

Write-In Nomination _____

Your Name: _____ Date: _____

Signature: _____

You can vote for up to four (4) people by placing a mark next to the appropriate person or make a write-in nomination. Please sign and date the form and send it to:

Hope Chest News
C/O Ed Aubitz
161 East 105th Street Circle
Bloomington, MN 55420

Forms must be received by July 18, 2008

Hope Chest News Database Updates

Update your Street Address

If your residence, home phone or cell phone has changed since you registered as a Hope Chest News member (or if you are not sure what address you used!), please provide your new address below:

Name: _____

Address: _____

City: _____ State: _____ ZIP: _____

Home Phone: _____

Cell Phone: _____

Update your Transplant info

We try to keep our individual members Transplant information up-to-date. Please let us know if any of the following are new or have changed. Due to HIPPA rules, Marget Schmidtke needs permission from patients to release their name, transplant number and date. She cannot release this information to Hope Chest News. Contact her (612-273-5796) for your transplant number.

Transplant Date: _____ Transplant Number: _____

Transplant Type: _____ (Single or Double Lung, Heart or Heart\Lung)

Update your E-Mail address

We recently started a new process to send out E-Mail notification of the U of M Support Group Monthly Meeting on the 1st Monday of the month. We used the E-Mail addresses recorded in the database when you registered with Hope Chest News. Several of the E-Mail addresses were rejected because they no longer exist! We would like to use E-Mail to keep you informed of new developments, meetings and special events. It is a easy, convenient and inexpensive form of communication. If you have a new E-Mail address or have never supplied yours and would like to, please provide it below.

Name: _____

E-Mail Address: _____

Fill in the information you want updated and send the page to:

Hope Chest News
C/O Ed Aubitz
161 East 105th Street Circle
Bloomington, MN 55420

Or you can E-Mail the information to hopechestnews@aol.com

Fund Raising

HCN fund raising efforts have increased in the last two years. In previous years we depended on donations or grants from people or organizations. Now we are able to use multiple ways to raise funds. Below are the 2008 sales and events that you can participate in that directly help our transplant patients in need.

Fund Raising Items For Sale

Item	Price	Contact	Phone #	Email
Cookbooks	\$15.00	Judy Vermeulen	952-445-2497	j avf pv@aol.com
Logo Tote Bag	\$15.00	Eileen Vier ow	651-483-3146	Eileenv10@hotmail.com
Logo Jackets	\$35.00	Eileen Vier ow	651-483-3146	Eileenv10@hotmail.com

Pancake Breakfast – Sunday, September 21st, 2008

Litchfield Eagles Club - 3424 S. CSAH 34 Litchfield, MN

Last year one of our members, Hal Wenaas, approached the Eagles club for a donation to Hope Chest News from their pull tab profits. Rather than giving a donation they allowed him to hold a fundraiser breakfast in their building. Hal needed 10 friends to help him and would get the profits from the breakfast after expenses. Last year it was held April 15th from 8am to noon. Hal had Pancakes, French Toast, Sausages, Juice, milk and coffee for only \$5.00. The event made over \$600.00 for Hope Chest News. Hal plans to do the same this year on Sunday, September 21st from 8am to noon. Hal's friends in Litchfield and a few people from Hope Chest have agreed to help again. Please consider taking a relaxing ride West to support this event.

* * * * *

4th Annual Daml Golf Tournament

A decision was made to postpone the 4th Annual Daml Golf Tournament from the original June 14th date to June 23rd because of conflicts with other tournaments. These conflicts seemed to be affecting registrations so the new date was able to be accommodated by the golf course. Because the Newsletter had a deadline to have the Annual Meeting publicized in enough time before the date, the results of the Daml event will be sent directly to the participant after the event is over. However, the results will also be included in the July - September issue

* * * * *

2nd Annual Marie Anderson Memorial Golf Scramble

Preparations for the 2nd Annual Marie Anderson Memorial Golf Scramble event are starting to accelerate. It will again be held at the Les Bolstad Golf Course on Monday, July 28th, 2008. The event has been expanded to include a Raffle for prizes of \$500, \$300 and \$100 as well as having the customary on-course games and contests

A 'flyer' for this event follows. Please feel free to use it yourself or to pass it to friends, family and co-workers. Ask them for participation in any of the categories; Event or Hole Sponsorship, Donation, Silent Auction item or as a player. Please send completed forms to Judy Vermeulen, 796 Regent Drive, Shakopee, MN 55379

Helping with these golf events

These golf events need people to make them happen! As a Hope Chest News newsletter recipient, you can help in several different ways:

- Recruit Event or Hole sponsors. The levels of participation are in the flyers.
- Provide an item for the Silent Auction. This is a very effective way of helping our cause. The most revenue comes from the Silent Auction
- Recruit golfers for the event. The more people who share the experience the better!
- Volunteer to help organize either of the events. This could be setting up the Silent Auction display, registration, processing the Silent Auction bids or cleaning-up at the end of the day.

Please feel free to copy the pages for the flyer and pass them to others. If you want a fresh, clean copy just contact one of the committee members listed in below and we will send them to you:

Hal Wenaas	320-593-7533	Gary Broberg	651-456-0340
Larry Daml	763-257-4967	Ed Aubitz	952-457-8281
Kip Peterson	952-431-8442	Judy Vermeulen	952-445-2497
Ross Bourgeois	763-522-6053	Eleen Vierow	651-483-3146

2nd Annual Marie Anderson Memorial Silent Auction

A major part of this event is the Silent Auction to be held after dinner at Elsie's. Last year the room was filled with happy golfers who finished the day supporting Hope Chest News by bidding on silent Auction items.

This year's Auction is shaping up to be even bigger and better than last year's. We have already received many nice items to put up for bids. A partial list as of this date follows. There are two very nice hand made items that are pictured here so you can see what will be available on the evening of July 28th.

Elliott Sovell made the Wood Canoe shaped bookcase. It is all oak and has a way to hang it on a wall if that is wanted. It is a beautiful piece of work which a black and white picture cannot do justice.

Kathleen Hallinan created several pieces of jewelry, only one is shown here. The pieces shown are made from red coral and turquoise and, like the bookcase, the true beauty cannot be shown in a black and white picture

Please stop by the dinner and see the assortment of 'goodies' even if you did not golf during the afternoon.



Wood Canoe Bookcase

Some items already received

Timberwolves, Vikings, Wild and
Twins gear,
Sun-protective clothing,
Wine and cheese baskets,
Movie themed baskets,
Free rounds of golf



Handmade jewelry

Marie Anderson

December 8, 1942 — October 10, 1997 — June 22, 2005



Marie Anderson was diagnosed with Alpha 1 Antitrypsin Deficiency, a genetic lung disease, in 1992. The disease continued to rob her of her capability to breathe, and in 1997 her doctors at the University of Minnesota put her on the transplant list.

Near death, Marie and her family were actually in the process of planning her funeral when she received a call from the University that a match may be available for her. On October 10, 1997 Marie received her gift of life when she underwent surgery for a bi-lateral single lung transplant.

Marie began to recover, and although she continued to experience set backs and side effects from the medications she now had to take to keep from rejecting her new lungs, Marie was never one to complain. She believed that each day was a blessing and one to be shared with others going through the transplant process. So selflessly, Marie spent endless hours at the U of M Transplant Center helping others as they went through their transplant journey. She helped to educate patients and their families, she spent countless hours sitting by a new patients bedside, brought food or an encouraging word, and did whatever else was needed to assist anyone going through transplant.

Marie was also on the Board of Director's for Hope Chest News. She felt adamant that Hope Chest News had to grow from an organization that provided education to patients and their families through a newsletter, to one that also provided financial support when needed. So, in 2003 Hope Chest News became a 501(c)(3) tax exempt organization with the mission statement that follows: "To support and educate the University of Minnesota Medical Center, Fairview patients and families as they progress through the process of heart/lung transplantation."

Hope Chest News grows we are finding that the needs of patients are changing also. The rising costs of medications, medical equipment and living needs continue to be a struggle for many.

Marie lived in June 2005 from complications of her transplant. She is committed to helping others and making a difference. We, the Hope Chest News, are committed to carry on her work.

The 1st Annual Marie Anderson Memorial Golf Tournament is being held to raise funds to continue that work to help others as they embark on their transplant journey.

Hope Chest

News

A 501 (c) (3) corporation



Presents

The 2nd Annual

Marie Anderson

Memorial

Golf Scramble

Monday July 28, 2008

Please check the appropriate circle(s):

- ☐ Gold (\$5000) ☐ Hole (\$300)
- ☐ Silver (\$3000) ☐ Hole (\$100)
- ☐ Bronze (\$1000) ☐ Player (\$110)
- ☐ I cannot attend the event, but have enclosed my donation of \$ _____
- ☐ I wish to golf in the tournament but need to be assigned to a foursome. Enclosed is \$110.00
- ☐ I would like to attend the dinner only, no golf. A donation of \$10 will be collected at the dinner.

☐ I would like to contribute the following gift(s) for the Silent Auction: _____ with a value of \$ _____

Please contact Ross Bourgeois (763-522-6053) to arrange for delivery of the item(s). Donated gift certificates must have expiration dates of no earlier than six months after July 28th, 2008.

For questions, please contact:

Hal Wenaas	(320) 593-7533
Gary Broberg	(651) 456-0340
Ed Aubitz	(952) 457-8281
Judy Vermeulen	(952) 445-2497
Kip Peterson	(952) 431-8442

Information & Schedule

2nd Annual Marie Anderson
Memorial Golf Scramble
Monday July 28th, 2008
Les Bolstad Golf Course
2275 Larpenteur Avenue W
St. Paul, MN 55113

11:00AM Registration and Lunch
Noon Shotgun Start
6:00PM Dinner, Silent Auction and Prizes
Elsie's
729 Marshall St NE
Minneapolis, MN 55413
(612) 378-9701

Prizes to the top 3 teams
Raffle for prizes of \$500, \$300 & \$100

\$10,000 Hole-in-one contest
Putting Contest, Card Draw, and more

Sponsorship Levels

Gold Level \$5,000

Company logo displayed at the course and dinner
2 hole Sponsorships with signage
12 golfer registrations\3 foursomes

Silver Level \$3,000

Company logo displayed at the course and dinner
1 Hole Sponsorship with signage
8 golfer registrations\2 foursomes

Bronze Level \$1,000

Company logo displayed on the beverage cart
4 golfer registrations\1 foursome

Hole Sponsorship \$300\100

\$300 Exclusive signage on one hole
\$100 Shared signage with other sponsors on
a hole

Golfer Registration \$110

Green fees, cart, lunch and awards dinner

Registration

1. Name: _____
Address: _____
City: _____ State: _____ Zip: _____
Phone: _____ Cell: _____
E-Mail: _____
Please list golfers in your foursome:
Foursome Name: _____

2. Name: _____
Address: _____
City: _____ State: _____ Zip: _____
Phone: _____ Cell: _____
3. Name: _____
Address: _____
City: _____ State: _____ Zip: _____
Phone: _____ Cell: _____
4. Name: _____
Address: _____
City: _____ State: _____ Zip: _____
Phone: _____ Cell: _____

Portable oxygen concentrators to be allowed on airlines

On May 8th the Department of Transportation (DOT) released the long awaited amendment to the Air Carrier Access Act that establishes mandatory rights for passenger owned portable medical oxygen concentrations that meet applicable DOT safety, security and hazardous materials requirements for safe use aboard aircraft. The DOT rule will also apply to foreign carriers that begin or end their flights in the United States. The Air Carrier Access Act enacted by Congress in 1986, prohibits airlines from discriminating against disabled passengers and now will include a provision long requested by oxygen advocates.

For now we will have to rely on the carriers that have voluntarily implemented carry-on for portable concentrators as the new rule takes effect on May 13 2009 to give airlines time to implement the regulation. You can read the final rule at www.regulations.gov, docket number DOT-OST-2004-19482. It is long at 75 pages!

Although this is a significant change in policy remember that this does not remove the need for advance notification and the proper medical documentation for the airlines.

The following concentrators have been approved by the DOT for patients to carry-on aircraft.

AirSep FreeStyle AirSep LifeStyle Inogen One Respiration EverGo
Sequal Eclipse

* * * * *

Alpha-1 Association News

The mission of the Alpha-1 Association is to identify individuals affected by Alpha-1 Antitrypsin Deficiency (Alpha-1) and to improve the quality of their lives through support, education, advocacy and to encourage participation in research.

The 17th Annual National Alpha-1 conference sponsored by the Alpha-1 Association was held in St. Louis - June 20-22nd, 2008. Special presentations on Saturday morning focused on the progress made on a cure for Alpha-1.

The next Alpha-1 Education Days are:

August 16	Lebanon, NH
September 20	Chapel Hill, NC
September 27	Las Vegas, NV
October 4	Boise, ID
October 18	Pittsburgh, PA

For more information on Alpha-1 Association programs or services visit:

Website: www.alpha1.org

Patient Information Hotline : (800) 245-6809

* * * * *

CF oriented 'blogs'

The following two Web sites were contributed by one of our members. They give insights into the lives and family members of people who have CF and have had received the 'Gift of Life'. We hope you receive inspiration reading their transplant journey stories.

cfhusband.blogspot.com

livinglifebreathlessly.blogspot.com

* * * * *

Idiopathic Pulmonary Fibrosis

National IPF Awareness Week 2008 is September 7th-12th

The Coalition for Pulmonary Fibrosis (CPF) is a 501(c)(3) nonprofit organization, founded in 2001 to accelerate research efforts leading to a cure for idiopathic pulmonary fibrosis (IPF), while educating, supporting, and advocating for the community of patients, families, and medical professionals fighting this disease. The CPF funds promising research into new approaches to treat and cure pulmonary fibrosis; provides patients and families with comprehensive education materials, resources, and hope; serves as a voice for national advocacy of IPF issues; and works to improve awareness of IPF in the medical community as well as the general public.

- Increase public awareness of IPF
- Provide education, information, and resources, and hope for patients suffering from IPF
- Serve as a national voice for our membership by advocating on their behalf in Washington
- Fund research into new approaches to treat – and ultimately cure - IPF
- Improve detection, diagnosis and treatment of IPF

With more than 10,000 members nationwide, the CPF is the largest nonprofit organization in the U.S. dedicated to advocating for those with pulmonary fibrosis. For more information please call (888) 222-8541 or visit:

www.coalitionforpf.org

or E-Mail them at **info@coalitionforpf.org**

The latest issue of the CPF Action Alert newsletter is available online at:

www.coalitionforpf.org/ofs/pdf/1Q2008newsletterfinal.pdf

Support Group Meetings:

Marget Schmidtke has supplied the following information about the speakers and topics for upcoming Monthly Meetings. Monthly meeting are held on the first Monday of the month from 7:00 – 8:30PM in the Lillehei Heart Institute Conference room. A Caregivers Support Group meeting precedes the patient Support group meeting from 6:00 – 7:00PM

July 7

Michael Petty, PhD(c), RN, CCNS, CNS

Cardiothoracic Clinical Nurse Specialist, University of Minnesota Medical Center, Fairview

Michael's Topic will be Self Care for the Caregiver....and the Patient

Michael has been the clinical nurse specialist on 6C/ D and the cardiovascular ICU working with transplant patients and their family for many, many years. He is currently doing his doctoral research paper on family caregiver issues. For more information about Mike please see the Web page

www.nursing.umn.edu/STTI/Board/PettyMichael.html

August 4

Joshua Breeding, Pharm.D., BCPS

Clinical Specialist, Cardiology/Pulmonology

Joshua's Topic will be Transplant Medications / Drug Interactions

Josh received his B.A. degree in biochemistry from Gustavus Adolphus College and went on to receive his Pharm.D. degree from the University of Minnesota. He then completed an ASHP-accredited pharmacy practice residency at the University of Minnesota Medical Center. Josh's areas of interest include heart failure, pulmonary hypertension and anticoagulation. He serves as the primary preceptor for pharmacy practice residents and acute care pharmacy students. Josh is Team Leader for the cardiology area.

September 1

There will not be a Group meeting in September because of the Labor Day holiday.

HOPE CHEST NEWS

PATIENT NEWSLETTER

Ed Aubitz

161 East 105th Street Circle

Bloomington, MN 55420



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Support Group Meetings:

- Weekly on Mondays at 11:00 a.m. (no day meeting on the first Monday of the month).
- Evening meeting only at 7:00 p.m. on the first Monday of each month.

Caregivers Support Group:

- First Monday of the month at 6:00 p.m. prior to the regular support group.

Sioux Falls Support Group:

- Contact June Schnieder at
605-339-3067

Annual Meeting and July Board Meeting

The Hope Chest News board of Directors will hold the Annual Meeting and its next monthly meeting on July 21st, 2008 in the 8th floor hospital conference room in the luncheon area from 12:30PM to 2:00PM. This is the “Bridges” Conference room. We encourage participation from all our members.