



HOPE CHEST NEWS

Spring 2010

HOPE CHEST NEWS, THE POSTAL SERVICE, THE ECONOMY AND THE ELECTRONIC AGE

At first glance, the items above may not seem to be connected. But, they are. March 15th was the monthly Board meeting for Hope Chest News and the primary agenda item was approving the budget for the upcoming year. A considerable amount of time was spent on the cost of printing and mailing the 450+ copies of the newsletter. The annual cost is budgeted at \$2,300 and that breaks down to about \$1.25 per issue when it is in your mailbox. Economic conditions have resulted in contributions to Hope Chest falling and the need for patient support is increasing. Due to increased costs for printing and mailing (remember that the Post Office is talking about dropping Saturday delivery to cut its losses) and the fact that a number of those receiving

the newsletter have an E mail address on file with Hope Chest News, the Board decided the following:

- This issue of Hope Chest News will go out by mail as it always has.
- Starting with the next issue, an electronic copy will be sent to everyone who has an E mail address on file. Those recipients will not be getting a mailed copy.
- At some point in the near future, it may be necessary to start charging mail recipients to defray printing and mailing costs.

This was not an easy decision for the Board because we realize that some may not feel comfortable using Email or might not have access to a computer. We hope everyone understands.

NEW FEATURES IN HOPE CHEST NEWS

This issue of Hope Chest News has some additions and changes. A new area will feature someone from the Transplant Center with each issue. Quite a few newsletter recipients don't have the opportunity to spend much time with some of the physicians and transplant coordinators. Each issue is going to include a profile of someone in the Transplant

Center that most patients will interact with at some point in their transplant journey. The other primary change in the newsletter is to publish in a 2 column format. Also, if anyone has ideas you would like to see included in the future, please let me know. Email Ross House at agsector@popp.net

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, heart or heart / lung transplantation, and to promote public awareness of the needs of these patients.

PRESIDENT'S MESSAGE

KIP PETERSON

I sincerely hope that this newsletter finds everyone well. Since our last newsletter we have had some changes within Hope Chest News. We have attempted to distribute duties and responsibilities to more members of the Board.

We are well aware that we



are a unique Board in that most of us are transplant patients. We realize that it is vitally important that we have as many people as possible who are able to fill in and take over as we never know when one of us may experience an illness or “bump in the road”.

Candace Sprout has taken over updating of the patient and caregivers data base, which is a huge job because of the constant activity of address changes etc.

Ross House has taken over putting together the newsletter and is also taking over the mentorship program. Both of these jobs are a big part of our mission statement.

Heidi Tuttle is going to be chairing the Marie Anderson Golf Tournament starting this year. For those that have not met her, Heidi is one of Marie's daughters. The above three jobs were all previously done by Ed. I can't tell you how that came about except that Ed always steps up to the plate when needed, kudos to Ed for that. As most of you know, Ed has taken over the responsibilities of Treasurer. Judy Vermuelen previously held that position for several years.

A week ago we set the budget for 2010. Candace, Ed, Kathy and I met for that project.

We had more requests for funds in 2009 than in previous years which we expected may happen. We were able to distribute \$30,000.00+ for heart & lung transplant patients.

We held a bake sale on March 15th in the Wagensteen building, a pancake breakfast is coming up on April 18th in Litchfield and, of course, the Marie Anderson Golf Tournament on July 26th.

Please consider participating in all of these events. I look forward to seeing you there! For those of you that haven't been involved--Please consider it! Take care / Have some fun

Kip

EVENTS AND NEWS

Upcoming Events

April 18, 2010: Pancake Breakfast sponsored by the Litchfield Eagles

July 26, 2010: h 4th Annual Marie Anderson Golf Tournament at Columbia Golf Course

Monthly Meeting of the Hope Chest News Board of Directors on March 21, April 19 and May 17 at 12:30 P. M. in the conference room of the Bridges cafeteria at U of M Fairview.

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.

Bake Sale a Great Success

The Bake Sale on March 15th netted a very respectable \$355. There was a great variety of

homemade sweets and sales were brisk. Thanks to Hinda Litman who organized the sale and to Gary Broberg, Kathy Greising, Betsey House, Tracy Lavigne, Kip & Barb Peterson, Marget Schmidke, Candace Sprout and Judy Vermeulen for baking such a nice variety of goodies and helping with the actual sale! Thanks also to Kathleen Hallinan for her help in creating the posters that were placed around PWB to publicize the sale.

There will be another Bake Sale on April 19th. We can always use more help with the sale or contributions of baked goods. Please contact Hinda Litman (952-935-1687 or hlitman@hotmail.com) if you can help out.

We have a new mailing address

At the October, 2009 meeting of the Board of Directors it was decided to use a centralized, non residential address for all mail addressed to Hope Chest News.

Our new mailing address is:

Hope Chest News
PO Box 13040
Minneapolis, MN 55414
The E-Mail address is still hopechestnews@aol.com



The Sioux Falls support group is facilitated by June

SIoux FALLS SUPPORT GROUP

Schneider. June is a Registered Nurse and spent time as a transplant coordinator with the VA

Hospital in Sioux Falls. For those waiting for a transplant, recipients and their families in

Southwestern Minnesota, northwestern Iowa and southeastern South Dakota, the group is a wonderful resource. Learn, exchange ideas and meet some new people. The meetings are on the 3rd Thursday

of each month. The meetings are held at McKennan Hospital in Sioux Falls at the Cancer Institute of the hospital and start at 7 P. M. June can be reached at 605-339-3067. You'll find a warm welcome and some great people.

2010 TRANSPLANTS

There have been 3 lung transplants and 1 heart transplant in 2010. The dates and transplant number for each are as follows:

Single lung on January 7, 2010 Transplant Number 387

Double lung on January 10, 2010 Transplant Number 221

Double lung on February 17, 2010 Transplant Number 222
Double lung on February 26, 2010 Transplant Number 223

Heart Transplant on February 3, 2010 Transplant Number 700

There is an interesting article about the 700th heart

transplant that was completed recently at Fairview University Hospital. The information is at the following [link: http://www.uofmtransplant.org/about/news/c_753866.asp](http://www.uofmtransplant.org/about/news/c_753866.asp)

The names of the transplant recipients aren't included because of HIPPA rules. Marget Schmidtke needs patient permission to release their name, transplant number and transplant date. Contact her for your transplant information then send it to the mailing address or E-Mail it to hopechestnews@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 ANNIVERSARIES

January - March

Matt Bartocci	DL	01/09/06	339	Karen Jacobson	SL	01/12/07
358 Mary Lee Carhill	SL	01/30/08	37	Dean Lanz	HL	01/04/97
186 Marge Engstrom	SL	01/31/00	339	Karen Jacobson	SL	01/12/07
338 Lester Fuhrmann	SL	01/04/07	169	Dennis Orlikowski	DL	01/07/98
229 Richard Hruza	SL	01/08/02	204	Mary Paquette	DL	01/10/08

231	Eva Quirk	SL	01/25/02	206	Jennifer Rousseau	DL	01/31/08
88	Stella Regenheimer	SL	01/27/95	377	Gary White	SL	01/25/09
	Michael Bluhm	SL	02/01/03		DuWayne Johnson	SL	02/06/06
33	Noreen Burke	DL	02/21/95	207	Ralph Loftus	DL	02/09/08
70	Rose Dalager	DL	02/05/98	340	Donna Meegan	SL	02/17/07
132	Brent DeBoer	DL	02/05/03		Linda Meyer	DL	02/14/02
123	Sharon Durante	SL	02/25/97		Hannah Joy Olson	DL	02/18/06
378	Mae Eastman	SL	02/19/09	341	M. Fern Olson	SL	02/20/07
84	Mark Gammon	DL	02/19/99	32	Sandi Peterson	SL	02/05/92
278	Maxine Golombiecki	SL	02/29/04	171	Bridget Shaffer	DL	02/18/06
208	Shelle Goodwin	DL	02/18/08		Sonja Sitzman	H	02/22/09
83	Ruth Heinen	DL	02/11/99		Barb Tackaberry	DL	02/07/02
	Bobbie Holmes	SL	02/14/06	211	Linda Tollakson	DL	02/17/09
				250	Sharon Warner	SL	02/10/03
				55	Gary Wulf	DL	02/20/97
	Shirley Baumberger	SL	03/09/06		Donald Eastman	SL	03/03/02
18	Brent Bowen	HL	03/23/90	207	Karen Fisk	SL	03/25/01
106	Richard Butschi	DL	03/22/01	154	Brian Frederick	DL	03/14/05
6	Grace Charboneau	DL	03/19/92	72	David Goroski	DL	03/13/98
381	Daniel Clay	SL	03/28/09		Peter Kosberg	H	03/01/07
104	Gail Deyoung	DL	03/19/01	204	Eugene Kuhns	SL	03/01/01
359	Clay B. DuVal	SL	03/26/08	160	Lyle Lohse	SL	03/16/99

IN MEMORY

We will miss these transplant recipients and those that were waiting. Our prayers go out to them and their families.

Kathy Desrochey on August 12, 2009. Kathy was waiting for a transplant.

Ron Daily on November 20, 2009. Ron received a lung transplant on December 12, 2005.

Sandra (Phillips) Sandager on February 19, 2010.

Sandy received a lung on August 3, 1998 and a kidney on September 25, 2004.

Susan Hackert on March 14, 2010. Susan received a single lung on September 12, 2006.

If you know of anyone else who has passed away, please let any of the Hope Chest News board members know.

Hope Chest News has received donations in memory of the following:

Eileen Fiore, a memorial from Ed Fiore

Ron Bowman, a memorial from Hazel Bowman

Donna Brown, a memorial from Paul Brown. Paul included the following note: Our continued thanks are rendered to the University of Minnesota Lung

Transplant program upon the 5th anniversary of Donna Brown's passing. During her time in the program you treated her with kindness and dignity. She was always indebted for the humane and kind treatment that she received at your capable hands. We wish all of the patients and staff great success as they continue on the road that she once followed. Donna would urge those of you who have the ability

to assist this program in any to please do so. Blessed be her memory from her husband, children and spouses, grandchildren, family and friends.

Scott and Lisa Olson, a memorial

Scott & Pam Tolve, a memorial

TREASURER'S REPORT

Ed Aubitz

A new development for Hope Chest News is to announce that it is now possible to make donations online using a credit card. The technology and dedication of one organization has made this possible, GiveMN.org. We have established an account at the GiveMN.org web site where you can go to make donations. Unlike retail transactions where a fee is paid by the merchant to the credit card company, Hope Chest will receive the full amount of your donation with no fees taken out. To use the GiveMN.org donation service:

- Start the program you use to go online; usually Internet Explorer or Firefox
- Type in the givemn.org Web address and press the Enter key on the keyboard
- Once you are at the Web page click in the box under the Donate\Find a nonprofit.
- Type in Hope Chest News and press the Enter key on the keyboard
- Click on the Hope Chest News logo
- A new window will be displayed where you enter the amount of your donation under the Make a Donation heading and then click on the Donate button
- There is a checkbox next to an entry of Add a designation. Clicking this checkbox opens a text box where notes can be entered. If this donation is for a memorial or honorarium please give the person's name in this box. There is no limit to the amount of descriptive text that can be entered
- Fill in the details of your American Express, VISA or Master Card
- If you put in your E-Mail address at the bottom of this window you will be sent a receipt for the donation.
- You can also elect to not have your contact information hidden from Hope Chest News using the checkbox at the very bottom of the window.
- Finish the donation by clicking on the Donate Now button at the bottom of the window.
- A new window is displayed confirming your donation. There is an offer of creating an account on another service called Razoo.com This is not required and clicking on the No Thanks button will bypass this
- You are finally put back in the GiveMN.org screen

Note that your donation will appear as Network for Good on your credit card statement. If you have any

questions please contact Ed Aubitz – 952-457-8281.

TRANSPLANT CENTER PROFILE

Dr. Marshall Hertz leads off a new feature for Hope



Chest News. Dr. Hertz is a Director at the Center for Advanced Lung Disease and is the Medical Director for the Lung Transplant Program. Dr. Hertz is Board Certified in internal medicine, pulmonary medicine and

critical care medicine. He attended medical school at the University of Michigan and his residency was at the University of Minnesota. Dr. Hertz indicates that he became interested in the transplant area

Because “During my residency training, I took care of many kidney, liver and heart transplant patients so I had built up some knowledge and experience in organ transplantation. I was new on the faculty at U of M when our first heart lung transplant was done in 1986. When I saw the dramatic improvement in that patient’s health after the surgery, I was hooked. As time passed I came to understand that the surgery itself is only one part of the process and that non-surgeons can play very important roles in pre and post transplant patient management.” His medical specialties are pulmonary and critical care medicine and both are a sub-specialty of internal medicine. His interests during free time are skiing, reading, piano and travel.

TRANSPLANT MORSELS – BITS OF INFORMATION

FINDING THOSE WITH COPD An article in the American Lung Association’s newsletter *Fighting for Air Online* relates that “About 24 million Americans suffer from chronic obstructive pulmonary disease (COPD). It’s a staggering number, made more so by the fact that only about half of them have been diagnosed. The rest, some 12 million, are unaware that they are living with a progressive, chronic illness that when detected and treated early enough, can be controlled and its impact on their quality of life

minimized. The challenge is finding and helping COPD’s missing millions. Chronic obstructive pulmonary disease (COPD), also known as emphysema and chronic bronchitis, is a very serious disease, and the fourth leading cause of death in the United States. The good news is that COPD is preventable and treatable. But like most diseases, the



COMPASSIONATE ALLOWANCES AND SOCIAL SECURITY DISABILITY

The following was recently published by the Coalition for Pulmonary Fibrosis: *Idiopathic Pulmonary Fibrosis (IPF) Included on Newest Disease Listing of Compassionate Allowances*. This is a huge step forward for patients and families fighting this disease and is due to the work of organizations like the National Organization of Rare Diseases (of which the CPF is a member). Patients will still be required to wait the mandatory 24-month waiting period to receive Medicare benefits, once approved by Social Security, but this "compassionate allowances" listing will at least shorten the wait on the front end for disability designation and benefits.

If you or a family member are in the process of applying for disability or have been previously turned down, please let them know about this new "compassionate allowances" listing. For help regarding your application or appeal for Social Security disability, you may reach out to our partner, the Caring Voice Coalition by calling 1-888-267-1440 or visit: <http://www.caringvoice.org>.

The Coalition for Pulmonary Fibrosis (CPF) is praising Social Security Commissioner Michael Astrue's announcement via press release that Idiopathic

Pulmonary Fibrosis (IPF), also known as Pulmonary Fibrosis (PF), and a listing of 37 other diseases and life-threatening medical conditions are the latest additions to Social Security's "Compassionate Allowances" program.

Compassionate Allowances are a way of quickly identifying diseases and other medical conditions that clearly qualify for Social Security and Supplemental Security Income disability benefits. It allows the agency to electronically target and make speedy decisions for the most obviously disabled individuals. In developing the expanded list of conditions, Social Security held public hearings and worked closely with the National Institutes of Health and the National Organization for Rare Disorders, of which the CPF is a member, and other groups. Social Security will begin electronically targeting these 38 new conditions, including IPF, March 1.

For more information about the agency's Compassionate Allowances initiative, go to www.socialsecurity.gov/compassionateallowances.

Note that the waiting period to start receiving Medicare benefits is unchanged and is still 24 months after being designated as disabled.



TO TELL THE TRUTH???

Ivanhoe's Medical Breakthroughs, December 8, 2009 reports that "Recent surveys conducted by Redbook Magazine and MSNBC indicate that 52-60%

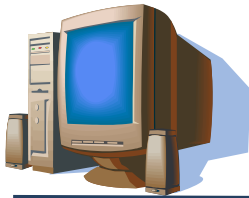
of participants claim to have "stretched the truth," or lied to their doctors and, 25% of them didn't think it was a "big deal." A study conducted by John Hopkins School of Medicine also found a big

difference between what patients said and what they actually did. Researchers there studied how often patients with breathing problems used an inhaler (the inhaler was equipped with a device that recorded the date and time the inhaler was used). The results??—73% of the patients reported using the inhaler three times a day (on average), whereas the data obtained from the inhaler recorders indicate only 15% of the patients used it that often; and about 14% had deliberately emptied their inhalers before their appointment to make

them look like they were “good patients”. Doctors say that many patients don’t realize their “fibs” can be harmful or even dangerous. Patients may lie because of embarrassment or because they don’t feel their doctor needs to know about that

part of their life, or because they don’t want to be judged. However, the more information a doctor has, the better it is to ensure that mistakes don’t happen.

WEBINAR ANNOUNCED



The U. S. COPD Coalition announced an interactive webinar to help those with chronic obstructive

pulmonary disease (COPD). The first presentation is on Monday, April 19, 2010 at 4 p.m. eastern time. For more information, go to www.COPDCoalition.org

ALPHA-FOUNDATION GRANT TO CONTINUE KEY GENETICS STUDY AFTER FEDERAL FUNDING DROPS

The National Institutes of Health (NIH) announced recently that it was awarding \$117 million to explore the epidemiology, diagnosis, and treatment of more than 95 rare diseases. The list of diseases to receive funding did not include Alpha-1 Antitrypsin Deficiency (Alpha-1). This ended funding, effective Oct. 31 this year, for a key Alpha-1 research effort called the Quantum-1 Study. The Quantum-1 study is designed to measure loss of lung function using CT scans, in Alphas who had normal lung function at the beginning of the study. When the NIH announced the decision to end funding for this Alpha-1 research, the Alpha-1 Foundation acted swiftly, authorizing a bridge grant of \$250,000 to continue the critical research program.

Charlie Strange, MD, principal investigator of the Quantum-1 Study, says that the biggest difficulty in getting new Alpha-1 drugs approved by the US Food and Drug Administration (FDA) is the lack of a short-term endpoint for therapy. “We think that a quantitative computed tomography (CT) scan directly measures emphysema—meaning holes in the lungs—better than any other measure,” says Strange. Our biggest challenge is to figure out the shortest interval of time that we can study individuals with emphysema to see if we can detect

lung density change. We need to know if a small density change is something meaningful that the FDA and, more importantly, our patients, will care about over time. A related goal is to determine the least amount of radiation necessary to collect accurate data. We’re grateful to the Alpha-1 Foundation for continuing support of this important study.” Strange says he and his colleagues are trying to prove to the FDA, clinicians, and patients, that a CT scan is the best tool for measuring the progression of lung disease.

He says the idea for the Quantum-1 Study originated several years ago, when doctors in seven major medical centers treating large numbers of Alphas had an opportunity to collaborate within the Rare Lung Disease Consortium at the National Institutes of Health (NIH).

“We could have studied any number of treatment trials, or tried new medicines,” Strange says. “We thought the need for a better outcome measure rose to the top of the list, however. Unless we can get a good endpoint for lung disease progression, no medicines will move through the FDA pipeline easily.”

Overall, Strange says, a disappointingly small number of drugs have come on the marketplace for Alpha-1 over the past 20 years. The Quantum-1 Study will accelerate the speed of discovery, he

believes. This could lead to an improved quality of life for Alphas. Forty-nine Alphas with normal lung function registered for the Quantum-1 Study, which began in 2007 and ends in late 2010. The final results will not be published until 2011. Strange says that the amount of emphysema doctors are already seeing on baseline scans from Alphas with normal lung function is surprising.

“This means that the process [of lung damage] is already beginning long before individuals have symptoms,” he says. “This also means that we could presumably intervene at an earlier time to prevent progression, if we had a medicine that would work.” Strange says that he had been optimistic that NIH would extend the Rare Lung Disease Consortium funding. However, the NHLBI chose to give lesser amounts of money to the Rare Disease Consortium

based in the Office of Rare Diseases than other institutes at NIH. Strange says the effect was to concentrate research on common diseases, rather than relatively rare ones. While he understands that decision, Strange says it might well have led to a missed opportunity. “Understanding how Alpha-1 emphysema progresses could provide clues to help cure other common diseases, such as non-Alpha-1 emphysema,” he points out. For now, Strange remains excited about the work on CT scan technology. “If we can prove that the CT scan makes a difference, we will have many more investigators and pharmaceutical companies participating in clinical trials with new medications.”

Abridged article, reprinted from Winter 2009 Alpha-1-to-1 magazine. For a free subscription, visit www.alpha-1foundation.org/publications

HOPE CHEST NEWS ONLINE

Hope Chest News is 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 computer. We can 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 journey; if you have questions or information you would like to share with other lung or heart transplant patients, please contact Ross House by

calling 763-593-9745 or via E-Mail to HopeChestNews@aol.com

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HOPE CHEST NEWS

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Address or E-Mail Change or Heart/Lung Status
Change: Candace Sprout 612 338-3419 or
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@popp.net

HOPE CHEST NEWS

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Universal Laws (Perhaps Written by Murphy)

Law of the Result - When you try to prove to someone that a machine won't work, it will.

Law of the Theater - At any event, the people whose seats are furthest from the aisle arrives last.

Law of Physical Surfaces - The chances of an open-faced jelly sandwich landing face down on a floor covering are directly correlated to the newness and cost of the carpet/rug.

Law of Logical Argument - Anything is possible if you don't know what you are talking about.

Brown's Law of Physical Appearance - If the clothes fit, they're ugly.

Oliver's Law of Public Speaking - A closed mouth gathers no feet.

THE FINE PRINT

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Wilson's Law of Commercial Marketing Strategy - As soon as you find a product that you really like, they will stop making it.

Law of Gravity - Any tool, nut, bolt, screw, when dropped, will roll to the least accessible corner.

Law of Probability - The probability of being watched is directly proportional to the stupidity of your act.