



# HOPE CHEST NEWS

**SUMMER 2010**

## Dan Oien To Celebrate 21st Anniversary of Transplant

Dan Oien’s transplant number is 11, so it’s been quite some time since his health struggle began. On July 8, 1989 he received a heart and new lungs and Dan will celebrate the 21st anniversary of his transplant this summer. He had primary pulmonary hypertension as well as an atrial septal defect in his heart.

Dan and his wife Pat live in Binford, North Dakota and have 2 children, Tanya and Stuart. The family spent 2½ years in Rogers,



Dan Oien and his wife Pat with their children Stuart and Tanya

just northwest of Minneapolis, while he waited for the transplant. They enrolled their daughter, Tanya in a local school. Their son Stuart was a pre-schooler at the time. The Oiens tried to lead a “normal” life as

Dan waited for the surgery. Dan says his primary goal was to see his children finish high school. Today, Stuart is 26 and Tanya is 30.

It has been a number of years since Dan has been at the Transplant Center at Fairview. He has his blood work, PFTs and X-rays done in Grand Forks, North Dakota and the information is sent electronically to the Transplant Center.

Dan says he has worn out a number of coordinators over the years. He is able to help his Dad, who at 86, still farms, with haying and some tractor work. Happy Anniversary Dan!!! Hope you have many more.

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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.

## Linda Tollakson's Transplant Story



Linda Tollakson

Linda Tollakson forwarded 2 articles that appeared in *The Western Guard* that featured her lung transplant experience. Linda lives in western Minnesota near the town of Dawson.

She suffered from COPD and on February 17, 2009 received a double lung transplant.

On February 3rd, 2009, she and her husband Roger, came to Minneapolis for an ap-

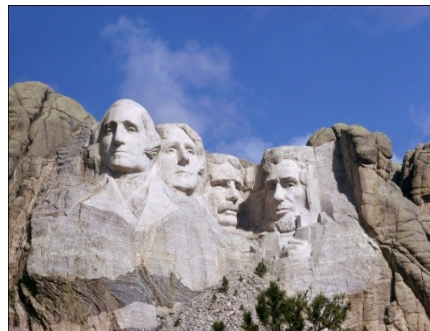
pointment the next day at the Transplant Center. On the morning of February 4th, Roger had difficulty waking her and she was taken unconscious by ambulance to Fairview University Hospital. Linda was suffering from high carbon dioxide level and was put on a ventilator. She remained unconscious until a week after the transplant surgery.

Linda says she was quite confused when she regained consciousness and learned that she had undergone surgery. Since the transplant, she has some leg weakness but is grateful to have received the gift of life.

## President's Message

I hope you are enjoying this wonderful spring and summer weather as much as I am. It is nice to be able to get outside and enjoy all the wonderful activities associated with our beautiful parks and lakes.

Our Hope Chest News Annual Board Meeting will be held this year on Monday, June 21, 2010. I would encourage all of you who can to attend. We are always looking for new people to step forward to become Board members. The more hands we have the more we can do. We are seeing an increased need for financial help among our patients and, as a Board; we believe that If we all do our share we can continue to meet those needs.



I would also like to remind all of you about the many fundraising opportunities we currently have available. The

Marie Anderson Golf Tournament is our largest fundraiser each year. This year it will be held on July 26<sup>th</sup> at the Columbia Golf Course. Dinner and silent auction will again immediately follow at Elsie's at 729 Marshall St. Minneapolis.

We have been holding bake sales in the

Phillips Wagensteen building across from the Outside In Cafe. Our next bake sale is scheduled for September, the exact date will be determined at the June Board meeting. Please consider contributing baked items. The more we have the better the Bake Sale.

It is now also possible to donate funds to Hope Chest News at any time online. Simply go to [givemn.org](http://givemn.org) and designate Hope Chest News for your gift. This is a fast and easy way to make a difference.

Finally, once again we have lost good friends in the transplant community. Frank

Vermeulen and Lyle Lohse were both a little over 10 years post transplant. Frank has been involved in Hope Chest for many years and Lyle always stopped by support group when he was in town. They will both be missed.

I look forward to seeing many of you at the Annual Meeting and at the Golf Tournament!

Enjoy your summer,

Kip Peterson

## Upcoming Events

June 21st is the Hope Chest News annual meeting. Officers and new board members will be elected. The meeting is held in the Bridges Cafeteria Board Room and begins at 12:30 P. M.

U of M support group meeting 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 June 21, July 19th and August 16 at 12:30 P. M. in the conference room of the Bridges cafeteria at U of M Fairview.

July 26, 2010: 4th annual Marie Anderson Golf Tournament at Columbia Golf Course. Information on registration for the tournament is on the following page.

# Hope Chest News

## Marie Anderson Memorial Golf Scramble

Benefitting U of M Medical Center heart and lung transplant patients

Monday July 26, 2010

Registration: 8:45 AM

Shotgun Start: 10:30 AM

Columbia Golf Course

3300 Central Ave. NE

Minneapolis, MN 55418



1st – 3rd place prizes

Putting contest

Hole games

\$10,000 Hole-in-One contest

Awards Dinner – 4:00PM

Elsie's Restaurant

729 Marshall Street NE

Minneapolis, MN 55413

Silent Auction – follows dinner

Registration form available online

[www.hopechestnews.org/Golf.html](http://www.hopechestnews.org/Golf.html)



## Litchfield Eagles Club Holds Pancake Breakfast To Benefit Hope Chest News

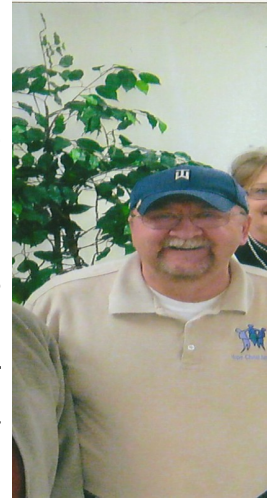


Litchfield Eagles Kitchen Crew

Hal Wenaas (double lung in 2001) has worked with the Litchfield Eagles Club for the last 4 years in putting on a pancake breakfast that helps support Hope Chest News. Hal says that this is the 4th year that the club has held the event and it has grown

every year. This year, they served 170 people. Hal is hoping that this year the breakfast will top \$1,000 for Hope Chest News.

The Club provides all of the help as well as the facility. Notices go out to all of the churches in Litchfield and the parking lot gets crowded. The Eagles Club and Hal deserve thanks for their help to transplant recipients.



Hal Wenaas

## Transplant Anniversaries April To June

214	Elizabeth Johnson	DL	04/20/09	112	M. Douglas Weasley	SL	04/01/96
648	Paula Karnuth	H	04/30/08	179	Harriette Wock	DL	04/11/06
287	Debbie Klietz	SL	04/03/05	134	Jim Audsley	DL	05/23/03
254	Andy Kronholm	SL	04/16/03	289	Thomas Bodmer	SL	05/31/05
85	Tracy Macius	DL	04/05/99		Kathleen Edmunds	SL	05/02/04
155	Jody Ogden	DL	04/01/05	290	Darrell Ehrike, Sr.	SL	05/31/05
	Shawna Ristau	DL	04/02/02	87	Kathryn Foss	DL	05/22/99
	Francis Steinke	DL	04/13/02	261	Bill Guthrie	SL	05/30/03
49	Carol Stimmel	SL	04/23/93	58	Greg Hules	DL	05/25/97

1	Ken Jones	HL	05/01/86	327	Todd Cram	SL	06/22/06
75	Kathie Justice	DL	05/25/98	94	Margert Doyle	DL	06/19/00
275	Fran Kaye	H	05/26/93	293	Leslie Fallstrom	SL	06/25/05
77	Carla Landreth	SL	05/21/94	191	Ann Fuhr	SL	06/14/00
24	John Marino	DL	05/23/94	364	Gloria Heideman	SL	06/25/08
157	JoAnn Miller	DL	05/01/05	107	Barbara Hinzman	SL	06/17/89
256	Karen Ness	SL	05/15/03	365	Renee M. Holzapfel	SL	06/25/08
324	Mike Olson	SL	05/19/06	39	Russell Hong	HL	06/21/97
166	Gene T. Phillips	SL	05/23/99	347	Vern Jackson	SL	06/20/07
20	Anna Piet	HL	05/24/90		Allen Jarnot	SL	06/05/08
360	Viola Poeschl	SL	05/02/08	25	Sandra Johnson	DL	06/21/94
215	Randy Forslund	DL	05/06/09		Larry Kershaw		06/26/05
	Darla Querry	DL	05/16/02	346	Worth Littlejohn	SL	06/02/07
145	Susan Saffel	DL	05/18/04	22	Larry Luttrell	SL	06/07/91
133	Gene Schrunk	DL	05/22/03	76	Robert Miller	DL	06/09/98
148	Daniel Tix	DL	05/09/04	32	Robert Miller	HL	06/03/94
86	Vincent Voelz	DL	05/14/99	93	Jeannine Santholzer	DL	06/19/00
326	Lonny Walker	SL	05/23/06	46	Shawna Waulk	DL	06/19/96
274	Ellen Weinand	SL	05/27/04	95	James West, PhD	SL	06/18/95
181	Jennifer Beitz	DL	06/25/06				

## Remembering Those Gone

Since the last newsletter, there are those who were involved with the transplant program who are gone. We will miss them and our prayers and thoughts go out to them and their families.

Joe Coletta, of Ramsey, MN on January 20, 2010. Joe received a single lung on August 11, 2004.

Robert “Bob” Haugen of Rockwell, Iowa, on

September 21st, 2009. Bob received a single lung on September 20, 2005.

Lyle Lohse of Isanti, MN on May 4, 2010. Lyle received a single lung on March 16, 1999.

Frank Vermeulen of Shakopee, MN on May 5, 2010. Frank received a single lung on December 3, 1999 and also a kidney subsequent to that.

## Donations and Memorials

Correction: The last issue of Hope Chest News listed a gift from Hazel Bowman for Ron Bowman. It should have been an honorarium.

A memorial in honor of Elizabeth Johnson's donor, Michael.

In memory of Lyle Lohse  
Shirley Lohse, Elaine Rhode, Wayne Anderson

In memory of Walter Rime:  
Karen Yeager, Marcia Blotske, Barbara Hoffer, Oleeta Rime, Valerie and Curtis Kinn, Diana Despres, Steven and Barbara Gazdik, Earl and Janice Cottingham, James Kathleen Kaiser and 2 anonymous donations.

In memory of Frank Vermeulen:  
Mary Ruff, Cynthia Weitzel, John and Karen Rusten, Sue Martin, Julie Caron, Hinda Litman, Gary and Marcia Wulf, Alana and Dennis Larson, Marty Davis, Mark and Debbie Podzimek, Ed and Sandy Aubitz, Michael Vermeulen, Wayne &

Barb Anderson, Dave & Cindy Boden, Paul Cummings & Anne Warfield. Mary Culhane, Larry & Ruth Doerfler, Tim & Penny Gendreau, Jim Gendreau, Marline Gannott, Tom & Carrie Gannott, Tom & Denise Groll, Dave & Jane Harty, June Johnson, Greg & Stacey Larson, Ross & Betsey House, Don & Donna Lane, Harlan & Pat Lehto, Ron & Nancy Madson, Joseph & Shirley Olson, Pat & Butch Pelava, Galen & Sherry Prail, Craig & Mary Rausch, John Runchy, Wayne Rierson, Bob & Ruth Siefert, Frank & Lucy Snijder, Jim & Chris Spense, Laura Tessmer, Greg & Jenn Wallace Kathy Greising and 1 anonymous donation.

A donation from Tom Bodmer.

The North Suburban Concert Band and those who attended the recent concert which designated Hope Chest News to receive the proceeds from the presentation. Lisa Olson, who plays in the orchestra, made it possible for Hope Chest to receive the show proceeds. The contributions totaled over \$2,000. Many thanks to Lisa and the North Suburban Concert Band.

## Recent Transplants

On March 26th there were 2 single lung transplants. They were number 388 and 389.

On April 3rd there was a double lung transplant, number 224.

April 5th, a single lung transplant, number 390.

A single lung transplant, number 391, on April 17th.

On May 15th there were 2 single lung transplants. They were number 392 and 393.

On May 16th a double lung transplant was done. That was number 225.

The names 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.

## Doing Less With Less?

The Minnesota Council of Non-Profits just completed a day long conference titled “Thriving in the New Normal”. One of the presenters talked about non-profits having to do less with less support due to the economy. Hope Chest News has 1 major fund raiser (the golf tournament) and 4 bake sales to raise funds. Donations are the only other source of dollars to help support those in need. The bulk of the work and support is from a core group of folks located in the Twin Cities. The 80-20 rule applies to Hope Chest News as well. 80% of the support and contributions come from 20% of the members.



For those living in Minnesota, there is an envelope enclosed to return a donation. We can only solicit a donation from Minnesota residents because Hope Chest News isn't registered in other states as a non profit.

Everyone's situation is different. Send what you can to help support those who have a need for monetary assistance in the transplant program. The funds are used to assist with housing, transportation, medications and publishing the newsletter.

## Transplant Center Profile



Dr. Maryam Valapour

Dr. Maryam Valapour is an Assistant Professor in both the Department of Medicine and the Center for Bioethics. She received her undergraduate degree in biology in 1988 from Charleston Southern University. In 1995, she completed her medical training at the Medical University of South Carolina. She spent a year as an Intern at Thomas Jefferson University in Philadelphia and served as a Resident in internal medicine there until 1998. Dr. Valapour was a Fellow in Bioethics and Health Policy at John Hopkins University in Baltimore. Also, from 1998 to 2002 she was a Fellow in Pulmonary and

Critical Care at John Hopkins. She came to the University of Minnesota in 2002 as an Assistant Professor at both the Center for Bioethics and the Department of Medicine. While here, Dr. Valpour has maintained an interest in medical ethics with regard to organ transplantation and organ allocation. In the Transplant Center, her focus is the evaluation of lung transplant candidates and the ongoing care of lung recipients.

Dr. Valapour is also a candidate to receive a Masters Degree in Public Policy from the Hubert H. Humphrey Institute of Public Affairs. She also has been a mentor to students interested in organ allocation.

In her free time, Dr. Valapour enjoys travel.



## Traffic And Construction Near the Transplant Center and Hospital

Construction has begun on the Central Corridor Light Rail Transit project and it will affect traffic in and around both the Phillips Wagensteen Bldg. where the Transplant Center is located and Fairview University



Hospital. Allow extra time if you have an appointment. The University is updating a website with construction information regularly. The information can be

found at: [http://www.lightrail.umn.edu/construction\\_current.html#traffic](http://www.lightrail.umn.edu/construction_current.html#traffic)

## Transplant Morsels—Bits Of Information

### Share Your Transplant Story in the 2<sup>nd</sup> Edition of *“Taking Flight: Inspirational Stories of Lung Transplantation”*

The 2<sup>nd</sup> Edition of *“Taking Flight: Inspirational Stories of Lung Transplantation”* is being compiled. Many transplant centers promoted the opportunity for the 1<sup>st</sup> Edition and hope they will again promote the 2<sup>nd</sup> Edition.

Just a brief outline of what this means:

1. It is free to submit your story.
2. Stories from Donor Family members, who donated lungs for donation are also encouraged to submit their story.
3. Carers and friends of those who had a lung transplant are also invited to share their unique and difficult duties as a carer. (I have experience as recipient and carer.)
4. Stories may be written by the recipient, a family member, friend or other person, if someone is not comfortable in writing their story. I am also able to write their story.

There are steps to follow in submitting stories, but easy to follow and I am always available by email or phone if anyone has questions.

5. The covers of the book will be designed by two of the contributors of the book. Original artwork only – photos, paintings, etc.

Profits from the book, once I recoup my expenses for publishing the book, will be divided among organizations, groups, both transplant and donor side, and research projects pertaining to lung transplant. The contributors of the stories will decide these organizations.

There are two ways in which one can learn about the process. The steps are listed at the new Facebook Group Site I created. (I will list that below). In the DISCUSSIONS section of the group site, are all the steps. Or, I can send personal emails to persons interested. If someone does not have a computer, mail, phone can communication can be arranged.

Please feel free to print out this information and distribute. Some centers are trying to get every recipient to contribute a story.

Any questions, feel free to email me: [lucky-lungsforjo@aol.com](mailto:lucky-lungsforjo@aol.com) Or [twolucky-lungs@juno.com](mailto:twolucky-lungs@juno.com)

Contact Information: Joanne Schum  
1104 Bay Road  
Webster, New York 14580

Phone: 585-671-7635

Here is the Facebook Group Information.  
Please feel free to join the group.

<http://www.facebook.com/home.php#!/group.php?gid=245756329913>

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### Medicare Part D Rebate

A \$250 rebate payment will be made to those on Medicare who have entered the part D drug coverage gap (doughnut hole) in 2010. The payments will start going out in June. The payment will be issued automatically to those that qualify.

### U Researchers Receive Grants To Improve Transplant Survival Rate

Dr. Chris Wendt and Dr. Marshall Hertz lead research aimed at improving transplant survival rates. 65% live longer than 5 years but rejection can be a major problem for some. 2 grants will fund research to predict rejection earlier.

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### New Therapies for Cystic Fibrosis

A recent article by Bruce Jancin in *Chest Physician* explains some promising therapies that are emerging for CF. Among the more promising are

- Modifiers of the CF transmembrane conductance regulator (CFTR )
- Airway surface liquid enhancers
- Osmotic therapy
- Anti-inflammatory agents
- Inhaled antimicrobials

- Gene therapy

Gene therapy has proven to be more difficult and complicated than researchers originally thought. The only clinical trial involves 100 patients in England.

Dr. Philip Marcus noted “Cystic fibrosis, an illness well understood mechanistically, has remained difficult to treat. We have been able to extend the life of those with the disease into early adulthood, primarily by the use of better antibiotics and mucus clearing agents.”

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### FDA Rejects Drug Treatment For Pulmonary Fibrosis

InterMune, Inc. announced that it the FDA refused to approve pirfenidone, its experi-

mental drug for use in treating idiopathic pulmonary fibrosis. At a meeting on March 9, the FDA advisory committee voted to recommend approval of the drug.

The FDA asked for new clinical trials to prove that the drug works. The denial could keep the drug off of the market for years. Initial trials had shown promise for the drug.

Had it been approved, pirfenidone would have been the first drug available to treat idiopathic pulmonary fibrosis. The rejection by FDA most likely means that it may be years before the drug might be approved.

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### Free Weekly E-Newsletter For Health Issues

*HealthDay*, an on-line provider of news for health related items, offers a free, personalized, electronic newsletter. To sign up for the free service, go to: <http://www.healthday.com/> on the Internet. On the lower left hand corner of the homepage,

there is a link to sign up for a personalized, weekly newsletter that will be delivered to your email address. The sign up allows each user to personalize what they receive. Topics range from alternative medicine to women's and men's health.

### Hope Chest News Contributions And Suggestions

Hope Chest News is published quarterly. This quarter, there are 2 articles about transplant recipients Dan Oien and Linda Tollakson. Personal experiences with organ transplantation help to provide a perspective for those waiting as well as those who have already received an organ.

If you would like to share your transplant story, contact me by phone at 763-593-9745 or by Email at [agsector@gmail.com](mailto:agsector@gmail.com). Also, if you have suggestions about anything that would be of interest, let me know. Thanks for your input (hopefully).

Ross House

### 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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Minneapolis MN 55414



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**Classified ads from U. K. newspapers:**

**FREE PUPPIES**

1/2 Cocker Spaniel, 1/2 sneaky neighbor's dog.

**FREE PUPPIES**

Mother, a Kennel Club registered German Shepherd . Father, Super Dog. Able to leap tall fences in a single bound.

**JOINING NUDIST CLUB**

Must sell washer and dryer. £100

**WEDDING DRESS FOR SALE**

Worn once by mistake. Call Stephanie.

**THE FINE PRINT**

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**FOR SALE BY OWNER**

Complete set of Encyclopedia Britannica, 45 volumes. Excellent condition — £200 or best offer. No longer needed; got married last month. Wife knows everything!

**COWS, CALVES: NEVER BRED.**

Also 1 gay bull for sale.