

NEWSLETTER

Winter 2023

BREATHING NEW LIFE BOARD OF DIRECTORS

Joe Stackhouse - President

Lori Kimm - Vice President

Deb Vreeman – Treasurer

Patty Wagner – Secretary

Laura O'Mara - Communications

Gary Grev - Director

Tammi Holets – Director

Lisa Stackhouse – Director

HOW TO CONTACT BREATHING NEW LIFE

Contact the board with ideas, concerns, or questions via email:

info@breathingnewlife.org

Or write to us at:

BREATHING NEW LIFE 6417 PENN AVE S STE 8 – 1210 MINNEAPOLIS, MN 55423-1196

VISIT OUR WEBSITE

Click here: Breathing New Life

WARM WISHES!

WELCOME to the Breathing New Life (formerly Hope Chest News) quarterly newsletter!

BREATHING NEW LIFE, a 501(c)(3) charitable organization, is comprised entirely of volunteers who are patients or are friends or family members of patients who have had, or are waiting for, lung transplants at the M Health Fairview UMMC. While the underlying diseases vary, we or our loved ones have each experienced an end-stage prognosis requiring a life-saving lung transplant. Many of the directors on the Breathing New Life Board are lung-transplant recipients and share the desire to give back to the lung-transplant community.

WHILE we are active in the transplant support group sponsored by the M Health Fairview social workers, Breathing New Life is a separate organization.

OUR MISSION: To educate and support M Health Fairview lung-transplant patients and their families, and to promote public awareness of transplant-related needs, so we may ease the financial burden of those patients most in need of assistance.

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This newsletter is published on a quarterly basis by Breathing New Life, a 501(c)(3) nonprofit organization. The information contained in this newsletter is not intended to be a replacement or substitute for professional medical advice. Consult your healthcare providers with any questions or concerns you may have about your condition.

SUPPORTING MHEALTH FAIRVIEW LUNG TRANSPLANT PATIENTS & FAMILIES



HAPPY NEW YEAR!

A new year is a perfect time for new beginnings. We are excited to announce the following changes we are implementing with the dawn of 2023.

New Name – We are now **BREATHING NEW LIFE**, effective January 1st, 2023! Our former name, Hope Chest News (HCN), has served us well for over 19 years; however, we believe Breathing New Life will better resonate with the MHealth Fairview lung transplant patients and families we support. Our new name inherently bears a relevance that we hope will increase name recognition as we continue to create awareness of our purpose.

All future contributions should be made payable to Breathing New Life.

New Logo and Tagline – We are proud to unveil our new logo, created to enhance and align with our new name, Breathing New Life. We have included the tagline, "Supporting MHealth Fairview Lung Transplant Patients & Families," to provide a glimpse into our mission. You will see our fresh look in quarterly newsletters, e-mail communications and stationery, as well as on our new website and social media.

New Website – Our much-anticipated, redesigned website launched January 1, 2023, as well! Through our new website, you will be able to donate to Breathing New Life and sign up for the Breathing New Life newsletters and e-mail communications (note, if you are already receiving HCN communications, you do <u>not</u> need to subscribe again; you are already in our database). You will also be able to see information about upcoming fundraising events and learn more details about our organization, just to name a few of the resources available. Check it out at breathingnewlife.org.

New Facebook Page – We now have a Facebook page for the Facebook fans! This new page will provide another resource to view information on our upcoming events. You will have the ability to send messages to Breathing New Life and link to our website via this page as well. You can find our new Facebook page here: BreathingNewLifeMN. Please "follow" us!

New E-mail Address - info@breathingnewlife.org

New Mailing Address – 6417 Penn Ave S Ste 8 – 1210 Minneapolis, MN 55423-1196.

New Mentorship Opportunity – Breathing New Life is pleased to endorse the *Joseph J. Carter Mentorship Program*, offered by the Lung Transplant Foundation (LTF). We encourage you to visit their website at <u>LTF Mentorship Program</u> to learn more about requesting a mentor or becoming a mentor, if interested.

Be assured, we are still the same 501(c)(3) nonprofit organization incorporated in 2003 and continue to be comprised entirely of volunteers who are patients or are friends or family of patients who have had, or are waiting for, lung transplants at the MHealth Fairview University of Minnesota Medical Center. We look forward to embarking on this new phase of our journey with you. Thank you for continuing to support us, as this enables us to support more lung-transplant patients and their families.

With gratitude,

Breathing New Life* Board of Directors (*Formerly known as Hope Chest News)

BREATHING NEW LIFE ENDORSES



FOR PATIENTS AND CAREGIVERS

- Are you a patient or caregiver interested in one-on-one support from a mentor in whom you could confide your concerns during your – or your loved one's – lung-transplant journey?
- Are you looking for a way to give back to the lung-transplant community after transplant and would enjoy mentoring other patients or caregivers?

If you answered "yes" to either of these questions, Breathing New Life (BNL) recommends that you consider requesting a mentor from or becoming a mentor for the mentorship program offered through the Lung Transplant Foundation (LTF).

As stated on the LTF website, the *Lung Transplant Foundation Joseph J. Carter Mentorship Program* was founded to provide support to patients and caregivers throughout the lung transplant process. Their trained mentors are passionate about encouraging those going through a lung transplant to be better able to handle the demands of this journey. Well-supported patients and caregivers lead to greater success for everyone.

Click on <u>LTF Mentorship Program</u> to learn more about the Lung Transplant Foundation's mentorship program, request a mentor, apply to become a mentor, or read about Joseph J. Carter, for whom the mentorship program is named.

Click on <u>LTF Mentorship-Program Brochure</u> to view or print the Lung Transplant Foundation's brochure, which also explains the mentorship program in more detail.

LTF matches mentees with mentors by commonalities: disease, age, and transplant center, when possible; therefore, BNL encourages transplant recipients (and their caregivers) who received their lung transplant at the MHealth Fairview University of Minnesota Medical Center (UMMC) to become mentors in LTF's program.

To meet LTF's requirements for becoming a mentor to a transplant recipient or caregiver, an interested candidate must:

- be at least 12 months post lung transplant
- complete the online "Become a Mentor" application
- be referred by a member of your transplant team
- complete an on-boarding phone interview
- finish all necessary paperwork prior to training
- successfully complete a 2-hour conference-call Mentorship Training

Mentor trainees participate in a live two-hour webinar conducted by the Mentorship Program Manager, LTF Executive Director, and Lead Mentors. In addition, they are provided with a Program Manual. Included in the training are confidentiality requirements, how to connect with and support the mentee, listening skills, role-playing scenarios, and how to respond to "red flag" situations.

COMING SOON!

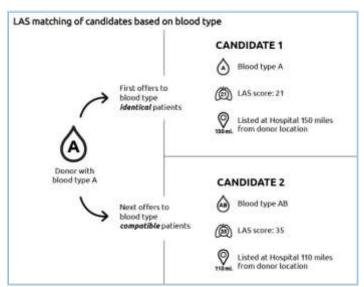
Lung Allocation Score (LAS) will change to Composite Allocation Score (CAS)

The Lung Allocation Score (LAS) policy, which has been in place since 2005, will transition to the Composite Allocation Score (CAS) by March 2, 2023.

LAS reflects how urgently each candidate needs a transplant and his or her chance of success following a transplant. In addition to their medical urgency, transplant candidates get priority for the lung(s) being offered based on factors such as their blood type, as well as how far their transplant hospital is from the donor hospital.

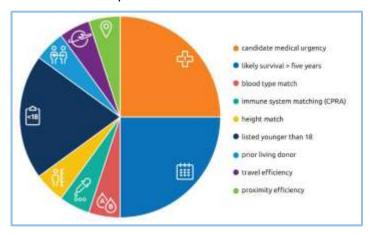
Although LAS has saved many lives and enhanced transplant survival over the years, it can be improved. Under the current policy, each matching factor is used to form a series of rules that set the order in which patients will be offered a lung transplant. This system can sometimes put too much emphasis on one factor when others may also be relevant.

For example, the current policy first provides lung offers for candidates who have the same blood type as the donor, with additional ordering based on their LAS. After that, other candidates who have a compatible (but not identical) blood-type match may receive lung offers. This approach may lead to a situation such as illustrated below.



In this example, Candidate 1, who has the same blood type as the donor, gets the first organ offer. However, Candidate 2, with a compatible blood type, would not get an earlier offer, even if he or she has a higher LAS and is listed at a transplant hospital closer to the donor hospital.

The new lung allocation policy will use the same patient factors already in the current matching system, while adding a few new attributes as indicated in this pie chart.



These factors are combined into a Composite Allocation Score (CAS). The CAS is individual for each patient and each organ offer. CAS point values represent each of the factors used to match organ offers with transplant candidates. The people who have the highest number of points for the lungs being offered will have the highest priority.

The CAS uses objective medical information about each candidate's needs and medical condition. It also uses objective medical facts about the potential organ donors that may be a match for the candidate.

The score weighs the different factors used to make the match. This means each factor will get a certain number of potential points, which are then added together to make up a maximum score of 100 points.

Some factors are more important in matching and will be worth more points within the overall score, while others get fewer points. Medical experts have carefully determined the weight for each factor based on the input from the transplant community as well as detailed statistical information.

(Continued on next page)

Half of the new CAS (up to **50 points**) will come from attributes similar to those used in the current LAS:

- Up to 25 points will be based on each candidate's medical urgency – how quickly he or she may need a transplant.
- In addition, up to 25 points will be based on the candidate's likelihood of surviving at least five years, if transplanted.

As many as **15 points** are reserved for candidates who are hard to match for some or most organ offers. This extra priority is meant to give more opportunities for lung offers that could be a match. There are three categories, each of which make up as many as **five points** toward the overall CAS:

- Blood type. Candidates with harder-to-match blood types will have more points than those who easier to match with potential donors.
- Calculated panel reactive antibody (CPRA) results. CPRA is a medical test that measures how likely a person is to have an immune system rejection to most organ offers. The higher the CPRA value, the greater the risk of rejection. For example, a person with a CPRA of 80 could not be a match with organs from 80 percent of donors. Patients with a high CPRA (harder to match) will get more points to qualify for offers that may match them. People with a low CPRA (easier to match with most donors) will have fewer points, or none, in this category.
- Candidate's height. Donor lungs must be a reasonable size match within the patient's chest. Patients who are much shorter or taller than average tend to get fewer matching lung offers than those who are of more common height. For this reason, candidates who are either very short or very tall will have more points to have better access to donors that could be a match.

Next, up to **25 points** are reserved for candidates who have special needs for access to a transplant:

 Candidates younger than 18 years old at the time of transplant listing will receive 20 points. Candidates who were living organ donors will receive five points.

The final portion of the CAS, worth as many as **10 points**, reflects the effort needed to preserve and transport the lung(s) from the donor to the recipient hospital. There are two parts to the transplant logistics, each of which can be as much as **five points**:

- Travel efficiency. This estimates the arrangements and expense needed to transport the lung(s) from the donor hospital to the transplant hospital. Donor/candidate matches with the greatest travel efficiency will be assigned the highest number of points (for example, if the donor and candidate are within the same hospital or at very nearby hospitals, or if the lung(s) can be transported by road instead of flight.)
- Proximity efficiency. This estimates factors, other than travel, in transporting the donor lung(s). The donor offers with the least complicated arrangements will be assigned the highest number of points (for example, matches that result in the shortest possible organ preservation time between donor and transplant hospital).

For more detailed information regarding the new lung allocation policy, click here: <u>CAS Q&A</u>

The Organ Procurement and Transplantation Network (OPTN) Lung Transplantation Committee will also host a webinar on **Thursday**, **Jan. 19**, **2023**, **from 3 to 4 p.m. EST** for transplant patients and their caregivers, regarding the upcoming policy changes. Click here to register for this webinar: CAS Webinar

As always, the transplant team at M Health Fairview UMMC will always be your first and most complete source of information regarding your current medical condition and treatment options.

Sources: United Network for Organ Sharing (UNOS),
Organ Procurement and Transplantation Network
(OPTN),

Health Resources and Services Administration (HRSA), an agency of the U.S. Department of Health & Services.



Patient Name	Transplant	Years Post	Type
	Date	Transplant	
Jackie Klatte	January 5, 2022	1	Double
Sherry Anderson	January 6, 2019	4	Double
Troy Cummings	January 10, 2021	2	Double
Bill Dickson	January 12, 2019	4	Double
Tom Fuller	January 14, 2011	12	Single
Richard Leske	January 23, 2020	3	Single
Julie Thiry	January 24, 2018	5	Double
Lan Ta	January 24, 2020	3	Double
Wally Preissing	January 27, 2013	10	Double
Gary Grev	February 3, 2012	11	Single
Rick Wirth	February 4, 2022	1	Double
Barb McKean	February 17, 2020	3	Double
Darlene Albrecht	February 22, 2018	5	Double
Reginald Tschetter	February 26, 2018	5	Double
Julie Satterlie	March 1, 2018	5	Double
Deb Vreeman	March 1, 2019	4	Double
Charlie Callahan	March 9, 2017	6	Double
Philip Messer	March 9, 2017	6	Single
Mike Germain	March 17, 2015	8	Double
Margie Arroyo	March 19, 2019	4	Double
Danny Busby	March 28, 2021	2	Double
Suzanne Brennan	March 28, 2022	1	Double
Shannon Carey	March 28, 2022	1	Double

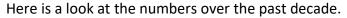
HELP US CELEBRATE YOU TOO!

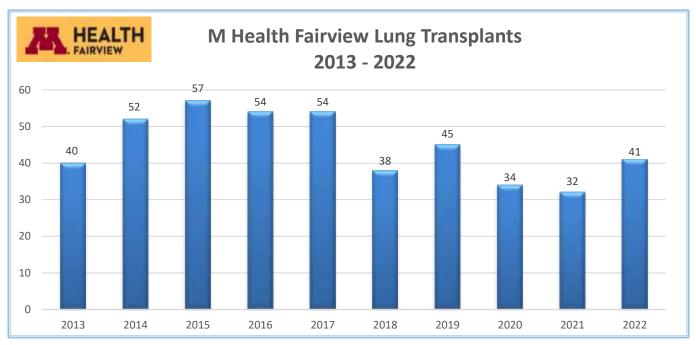
To be recognized in Breathing New Life newsletters, provide your transplant information by using this link to our database: BNL Database

NOTE: You must choose the option to grant permission to Breathing New Life to recognize your transplant anniversary in future publications of our newsletter. Due to HIPAA, we are not permitted share patient transplant dates without the patient's permission.

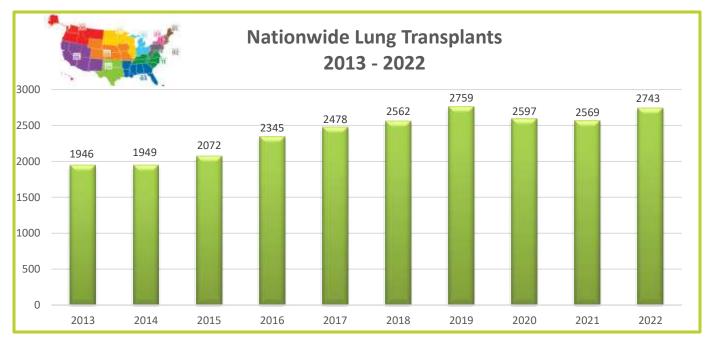
LUNG TRANSPLANT STATISTICS

The Transplant Center at M Health Fairview University of Minnesota Medical Center (UMMC) performed **41** lung transplants throughout 2022.





There are currently **75** lung transplant centers in the United States compared to **65** centers 2013. Lung transplants performed by M Health Fairview UMMC account for roughly **1.5**% of all lung transplants performed in the United States.



^{*}Nationwide figures include heart/lung transplant procedures

SUPPORT GROUP INFORMATION AND RESOURCES

M Health Fairview UMMC lung transplant social workers host weekly patient/caregiver and monthly caregiversonly support groups.

Weekly Patient/Caregiver Support Group

The Lung Transplant Support Group meets virtually (via Zoom) once a week on Mondays from 11:00 am – Noon CT.

If you would like information about how to join the zoom meeting, please contact:

Marget Schmidke, LICSW

Marget.Schmidtke@fairview.org or 612-273-5796

Liz Herman, LICSW

Liz.Herman@fairview.org or 612-273-4579

Weekly Lung Transplant Support Group is open to all patients and their caregivers who are being evaluated for, have been listed for, or have received a lung transplant at M Health Fairview UMMC.

The Lung Transplant Support Group offers the opportunity for patients and caregivers to learn about transplantation firsthand from others who have been on this journey. It is a safe and confidential forum to ask questions, share experiences and feelings related to transplant. People in the group who have shared experiences often develop close bonds with one another.

Monthly Caregivers-only Support Group

Caregivers-only Support Group meets virtually (via Zoom) on the first Monday of every month from 6:00pm - 7:00pm.

If you would like information about how to join the zoom meeting, please contact:

Marget Schmidke, LICSW -

Marget.Schmidtke@fairview.org or 612-273-5796

Liz Herman, LICSW

Liz.Herman@fairview.org or 612-273-4579

Monthly Caregivers-only Support Group is offered on the first Monday of each Month and is specifically for Caregivers ONLY. This is a safe place for caregivers to share feelings, ask questions, support one another as you care for your loved ones.

Support Group Holidays

Support Group(s) will not be held on these dates:

- May 29, 2023 Memorial Day
- September 4, 2023 Labor Day
- December 25, 2023 Christmas Day
- January 1, 2024 New Year's Day

HELPFUL WEBSITE LINKS

- HealthWell Foundation (medication expense assistance)
- Wilder Caregiver Support and Resources
- LifeSource
- Alpha-1 Foundation
- COPD Foundation
- Cystic Fibrosis Foundation
- Cystic Fibrosis Research Institute
- Pulmonary Fibrosis Foundation

FACEBOOK SUPPORT GROUP LINKS

- Minneapolis MN Lung Transplant Support Group
- Lung Transplantation Taking Flight with New Life
- CF Lung Transplantees
- Alpha-1 Antitrypsin Deficiency Support
- COPD Support Group
- Cystic Fibrosis Community
- <u>Pulmonary Fibrosis Information by Breathe</u>
 Support
- Ultimate Pulmonary Wellness

DONATE MEDICAL EQUIPMENT

<u>Global Health Ministries</u> located at 7831 Hickory St NE, Fridley, MN 55432 would welcome your gently used medical equipment and supplies that you no longer need. GHM cannot take medications or items with an expiration date that is less than a year out. Call 763-586-9590 if you have supplies or medical equipment you would like to donate.

UPCOMING EVENTS

Mark these fundraising events – which support Breathing New Life (BNL) – on your calendar. Your attendance at these events helps Breathing New Life achieve our mission. Not available? Can't golf? Consider a donation!

Save the Date!			
WHAT	Breathing New Life Pancake Breakfast	Breathing New Life Golf Tournament	
WHEN	Sunday, April 23, 2023	Saturday, July 29, 2023	
WHERE	Litchfield Eagles Club 389 CSAH 34 S Litchfield, MN 55355	Goodrich Golf Course 1820 Van Dyke St. Maplewood, MN 55109	
MORE INFORMATION	Please join us for a great cause and a delicious breakfast of pancakes, French toast, sausage, juice, and coffee!	Watch for details on our website, in BNL email communications, and on facebook.	
	This is our second-largest fund-raising event of the year.	The BNL Annual Golf Tournament is our largest fund-raising event of the year.	
	Adults – \$10.00 Children 10 and under – \$5.00 TAKEOUT AVAILABLE	QUESTIONS: please contact Hal Wenaas - 320-593-7533	
	NOTE: Hal Wenass, organizer of this event, will be celebrating his 22 nd anniversary of his successful double-lung transplant in October 2023. Since his transplant, Hal & his friends have been raising money to help other patients going through lung transplantation.	Gary Grev - 763-258-7900 GOLF COURSE	

"NO ACT OF KINDNESS, NO MATTER HOW SMALL, IS EVER WASTED."

OTHER WAYS TO SUPPORT BREATHING NEW LIFE

Here are additional ways you can support Breathing New Life any time of the year.

COMING SOON! We are designing new T-shirts with our Breathing New Life name and logo. Stay tuned for more information on how to obtain yours once they are available.





Purchase a Hope Chest News T-Shirt *WHILE SUPPLIES LAST!

COST: \$15.00 \$10.00 - Sale Price! + \$5 to cover shipping costs.

To order: email Gary Grev at grevga@comcast.net.

*Limited sizes/quantities available:

Size	Qty
2X	1
Medium	3

Donate with Amazon Smile

- Visit https://smile.amazon.com
- Select <u>Hope Chest News</u> as your charitable organization. Please note, we are working with AmazonSmile to update our name to Breathing New Life in their system and will communicate if there are any additional steps an AmazonSmile user needs to take.
- Shop away! Every eligible purchase you make via <u>https://smile.amazon.com</u> will result in a donation to our organization.

Hope Chest News received **\$184.30** in donations from AmazonSmile in 2022.



Donate in Honor or Memory of a Transplant Patient

If you would like to donate on behalf of a transplant patient, you may visit our <u>Give MN Donations page</u> or mail your check to:

Breathing New Life 6417 Penn Ave S Ste 8 - 1210 Minneapolis, MN 55423-1196





FINANCIAL SUMMARY

For the Year ending 12/31/2022

STATEMENT OF ACTIVITIES		Jan – Dec 2022
REVENUE	Corporate contributions, memorials & honorariums, individual contributions, pancake breakfast, t-shirt sales	\$24,931
	Golf Tournament Revenue	\$35,343
	Interest Earnings	\$4
	Total Revenue	\$60,278
EXPENSES	Golf Tournament Expenses	\$10,541
	Grants/Patient Financial Assistance	\$40,780
	Operations	\$2,301
	Other Expense	\$39
	Total Expenses	\$53,661
2022 CHANGE IN NET ASSETS		\$6,617

FINANCIAL GRANTS BY YEAR					
FIVE-	YEAR	NUMBER OF GRANTS	TOTAL AMOUNT		
	2022	35	\$40,780		
	2021	26	\$20,707		
YEAR SUMMARY	2020	31	\$33,268		
	2019	39	\$31,756		
	2018	28	\$15,094		

Note: As of December 31, 2022, our organization's name was Hope Chest News. Our name changed to Breathing New Life, effective January 1, 2023.

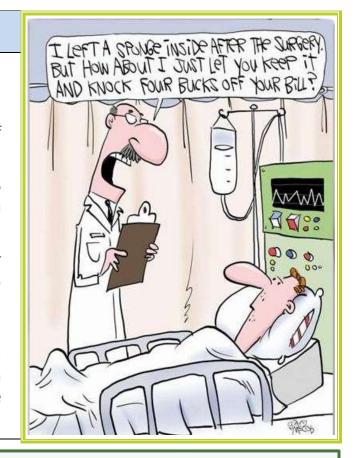
JUST FOR FUN!





DID YOU KNOW?

- The lungs are the only organs that can float on water.
- An average person loses almost half a quart of water every day through breathing.
- The air we breathe contains approximately 21% oxygen, but our bodies swap about 5% for carbon dioxide, which we exhale.
- ❖ Birds can intake twice as much oxygen in their lungs. They are the most efficient breathers among all animals.
- "Mouth breathing" can actually change your face. Researchers found differences in the facial developments of children who breathe through their mouths compared to children who breathe through their noses.



No one thinks much about their ability to breathe; they just do it.

It's when a person can't breathe, that they suddenly realize they'd been doing something truly marvelous all along.

~ Susan Meissner



PRESIDENT'S REPORT

Welcome to 2023!

I hope you had a wonderful holiday season and that your 2023 is off to a great start.

Breathing New Life, formerly Hope Chest News, had an exciting year in 2022. We are so fortunate and grateful for all those who contribute. We were able to provide 35 financial grants to people on their journey with lung transplant. We are so honored to be part of the journey and could not do it without our volunteers, donors, and golfers. We will never forget that our priority is walking beside those on their lung transplant journey.

As you see, we changed our name effective January 1st. The name Hope Chest News served us very well for almost twenty years. The board decided it was time to change our organization's name and image to something more closely matching the amazing transformation new lungs can bring.

We will challenge ourselves in 2023 to have an even greater positive impact to those receiving lung transplants.

Cheers to a wonderful 2023!

Regards,

Joe Stackhouse

President Breathing New Life