SUPPORTING **M HEALTH FAIRVIEW** LUNG TRANSPLANT PATIENTS & FAMILIES

# NEWSLETTER

Fall 2023

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ATHING

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#### 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 7 – 1210 MINNEAPOLIS, MN 55423-1196

#### **VISIT OUR WEBSITE**

Click here: Breathing New Life

# Fall Is Upon US!

**BREATHING NEW LIFE** (BNL) is a 501(c)(3) charitable organization 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 hosted by the M Health Fairview social workers, Breathing New Life is a separate organization.

**OUR MISSION:** To educate and support M Health Fairview lungtransplant 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.

## IN THIS ISSUE

- Introducing Dr. Anupam Kumar
- Support Group Information
- Writing to Your Donor's Family
- Transplant Anniversaries
- A Patient's Perspective: Valerie Flood
- From the Caregiver's Corner: Lionel Flood
- Give to the Max Day 2023
- Volunteer For Breathing New Life
- Other Ways You Can Help Breathing New Life
- Purchase a Breathing New Life T-shirt!
- Know the Nonprofits
- Helpful Resources
- President's Report

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.

#### Introducing Dr. Anupam Kumar, MD, FCCP University of Minnesota Lung Transplant Program Medical Director

Dr. Anupam Kumar found time in his busy schedule to answer a few questions for the Breathing New Life newsletter. Our questions and his answers are below, but he will be available to answer additional questions as the special guest at the November 6<sup>th</sup> support group meeting at 11:00 a.m.

# What inspired you to become a physician and, subsequently, specialize in pulmonology and lung transplantation? My deep-seated desire to impact lives through healthcare was



inspired by my father, a physician. During my undergraduate medical studies, I became captivated by the intricacies of the lungs, leading me to pursue a career in pulmonary medicine. Lung transplantation, with its potential to provide a second chance to those with advanced lung diseases, became my passion. Witnessing the transformative impact of transplant surgery on patients' lives is incredibly rewarding. I'm drawn to the difference it makes in enabling people to enjoy a life they might otherwise have lost

What is your vision for the University of Minnesota (UMN) lung transplant program? The University of Minnesota's lung transplant program has been a pioneer in transplantation for over three decades. My vision for this program is to expand our services, reaching people in need of lung transplantation regionally and nationally. With our expertise and legacy, we can achieve this goal. I am committed to delivering comprehensive, cutting-edge medical care to our patients, granting them access to the latest research and innovations in transplantation. My motivation stems from a strong desire to offer our patients the best possible experience and outcomes. We aim for you to take pride in your association with the University's lung transplant team.

Do you anticipate that any changes or improvements you wish to make to the UMN lung transplant program will have a noticeable impact on current patients? If so, could you elaborate? Our primary focus will be on addressing the complex needs of a wide array of potential lung transplant recipients. We will make it a priority to reduce evaluation delays and streamline post-transplant care processes. Moreover, we are committed to expanding our access to cutting-edge transplantation innovations and offering our patients opportunities to engage in research studies. I have full confidence in our ability to maintain our commitment to delivering world-class care for our patients

You have many responsibilities as the Director of the UMN lung transplant program, yet you're staying involved in patient care. Why is it important to you to keep the direct connection to patients? I have numerous responsibilities as the Director of the UMN lung transplant program, but remaining engaged in patient care is essential to me. I find great fulfillment in personally connecting with those in need. It's this very connection that initially led me to the field and continues to drive my passion. In lung transplantation, the relationship between patients and doctors often becomes a lifelong bond, and no matter my administrative duties, I will always prioritize staying connected with my patients.

As you may know, many patients struggle with the decision to be listed for a lung transplant. If you were told you needed to have a lung transplant, what are the factors you would take into consideration when making your decision to proceed? That's an excellent question. If faced with the need for a lung transplant, I would weigh several factors in making my decision. Firstly, I'd consider my current quality of life and life expectancy without a transplant, as well as the potential improvements and opportunities for a fulfilling life after the procedure. If I believe that a transplant would enable me to breathe without the need for oxygen, spend valuable time with loved ones, and pursue the activities and experiences I cherish, I would be inclined to proceed with the transplant. Ultimately, the decision would be based on my determination to continue living a purposeful life.

What are you looking forward to experiencing most now that you're living in Minnesota? I'm most excited about experiencing the beautiful fall colors, enjoying lake adventures, and discovering the essence of "Minnesota nice."! I also look forward to fostering new friendships within and outside work.

What else would you like us to know about you? I have a deep passion for world history, and am a decent cook in the kitchen. When I'm not on the job, you'll find me exploring new places through travel or sharing fantastic moments with my incredible children.

# SUPPORT GROUP INFORMATION

M Health Fairview UMMC lung transplant social workers host weekly patient & caregiver support groups and monthly caregivers-only support groups. These support groups are currently being held via Zoom.

Weekly Patient/Caregiver Support Group	Monthly Caregivers-only Support Group		
The Lung Transplant Support Group meets virtually (via Zoom) once a week on Mondays from 11:00 am – Noon CT.	Caregivers-only Support Group meets virtually (via Zoom) on the first Monday of every month from 6:00pm - 7:00pm CT.		
If you would like information about how to join the zoom meeting, please contact:	If you would like information about how to join the zoom meeting, please contact:		
Marget Schmidke, LICSW	Marget Schmidke, LICSW		
Marget.Schmidtke@fairview.org or 612-273-5796	Marget.Schmidtke@fairview.org_or 612-273-5796		
Liz Herman, LICSW	Liz Herman, LICSW		
Liz.Herman@fairview.org or 612-273-4579	Liz.Herman@fairview.org_or 612-273-4579		
Weekly Lung Transplant Support Group is open to all patients who are being evaluated for, have been listed for, or have received a lung transplant at M Health Fairview UMMC. Caregivers of these same patients are also welcome to attend. The Lung Transplant Support Group offers the	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, and support one another while caring for loved ones who are waiting for, or have had, transplants.		
opportunity for patients and caregivers to learn about transplantation firsthand from others who have been	Monday Holidays		
on this journey. It is a safe and confidential forum to	Support Group(s) will not be held on these dates:		
ask questions, share experiences and feelings related to transplant. People in the group who have shared	• December 25, 2023 - Christmas Day		
experiences often develop close bonds with one another.	<ul> <li>January 1, 2024 - New Year's Day</li> </ul>		

#### ALERT! November 6<sup>th</sup> Support Group Meeting Special Guest, Dr. Anupam Kumar

#### University of Minnesota Lung Transplant Program Medical Director

We encourage patients and caregivers to join the virtual Lung Transplant Support Group on Monday, November 6<sup>th</sup> at 11:00 a.m. to meet the new University of Minnesota Lung Transplant Program Medical Director, Dr. Anupam Kumar.

To join the Zoom meeting, click on this link Support Group Zoom, prior to 11:00 a.m., CT:Zoom Meeting ID: 981 5543 0951Zoom Meeting Passcode: Lung22

Or you may listen by dialing in with this phone number: 1 651 372 8299 US Dial-in Meeting ID: 981 5543 0951 Dial-in Passcode: 762529

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#### WRITING TO YOUR DONOR'S FAMILY

With the Thanksgiving holiday just around the corner, this is a perfect time to express your gratitude to your lung donor's family. Those who have already written that "first letter" say it will be the toughest letter you will ever write. Keep in mind, it's to convey thanks for a priceless gift and condolences to a family who has lost a loved one who was in good health. It's further complicated by the fact that you are writing to an anonymous family with no, or very few, specifics from which to draw your thoughts.

Fortunately, LifeSource has created letter-writing FAQs & tips to help with this endeavor. You can learn more, and can even submit your letter electronically, by completing the online form here: <u>WritingtoDonorFamilies</u>.

LifeSource offers these suggestions to help with any writer's block you may be having.

#### Share general information:

- Your name.
- The state in which you live.
- Your job or occupation.
- Your hobbies or interests.
- Your family situation, such as marital status, children or grandchildren.

#### Talk about your transplant experience:

- Use simple language; refrain from using too much medical terminology.
- Recognize the donor family and thank them for their loved one's gift.
- Describe how long you waited for a transplant.
- Share what the wait was like for you and your family.
- Explain how the transplant has improved your health and changed your life.
- Explain what has happened in your life since your transplant?
- Did you celebrate another birthday?
- Did your son or daughter marry?
- Did you become a parent or grandparent?
- Did you return to school or accept a new job?

#### Use caution:

- The donor family's religious beliefs are unknown, so please consider this if you are thinking of including religious comments.
- Avoid referring to your transplanted lung(s) by a nickname.

You certainly don't need to touch on all of the items on the above list. There is no right or wrong way to let your donor's family know how grateful you are. Whether you send a small notecard; a big, fancy card with a long letter; or LifeSource's online form, the important thing is that the words come from your heart.

If you're concerned your letter will cause more pain, or serve as a reminder of their loss, please don't be. The donor's family thinks of their loved one every single day; your letter is not going to remind them. On the contrary, many donor families have said a card or personal note from their loved one's recipient offers them comfort. Even if you don't hear back from the family for a while, if ever, you have let them know something positive came from their loved one's death.



Patient Name	Transplant Date	Years Post Transplant	Туре
Hal Wenaas	October 7, 2001	22	Double
Eunice Zimprich	October 17, 2005	18	Single
Tammi Holets	October 24, 2020	3	Double
Gail Baumgart	October 28, 2000	23	Double
Lisa Stackhouse	October 29, 2015	8	Double
Lynn Wagner	November 7, 2017	6	Double
Albert Davis, Jr.	November 9, 2019	4	Double
Grant Rappe	November 13, 2019	4	Double
Debra Mertens	November 16, 2017	6	Double
Chris Mann	November 28, 2018	5	Double
Denise Stoen	December 9, 2014	9	Single
Jim Haigh	December 16, 2020	3	Single
Lori Kimm	December 19, 2016	7	Double
Jamie Hammer	December 21, 2010	13	Double
Bryan Hayden	December 23, 2020	3	Double
Susan Mason-Lommen	December 30, 2019	4	Double

#### HELP US CELEBRATE YOUR ANNIVERSARY TOO!

To be recognized on our anniversary page in future newsletters, you need to be in our database. Send an email with the following information to <u>info@breathingnewlife.org</u>.

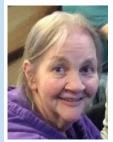
- First & Last Name
- Transplant Date

• Email Address

• Transplant Type (single vs. double)

NOTE: By providing your information, you are agreeing to being added to our email database and granting permission to BNL to recognize your transplant anniversary in future publications of our newsletter.

## A PATIENT'S PERSPECTIVE – Valerie Flood



"It didn't faze me at all," Valerie (Val) Flood says of her May 5, 2023 double-lung transplant, "because I knew I needed to have it done. Her lack of concern going into the surgery is surprising given a pre-evaluation conversation she had with a transplant pulmonologist. Valerie describes the information she was given on that call as a "horror story" of all the things that could go wrong after transplant.

In May, 2022, the beginning of her very long, protracted evaluation, she met with a different pulmonologist who did not paint such a dire picture of lung-transplant outcomes in general,

but he did tell Val that he didn't feel comfortable putting her on the transplant list. He felt she was frail, and the transplant surgery would do her more harm than good.

At that time, she was experiencing pressure on the left side of her heart, preventing her heart from fully functioning. She had started taking Entresto and Tyvaso, an inhaled treatment that can treat pulmonary arterial hypertension, and was mid-course when she got the news that she would not be getting a transplant. As the rest of her test results, as well as her therapy results, were still outstanding - and would continue into the new year - the final decision was put on hold. After Val completed the inhaled therapy, subsequent testing showed her heart was now stronger. Her heart doctor explained that it was her lungs that were causing the heart problems and if she were to receive a lung transplant, her heart would continue to improve.

Val had a subsequent appointment with the transplant surgeon, who observed that she was stronger than she had previously been at the start of her evaluation. He was now willing to recommend she be reconsidered for a transplant. After her transplant, the same surgeon told Val, "You know, you showed us what you had before transplant, now show us what you have after surgery."

Val, typically a self-sufficient and independent person, was concerned she may need more help after transplant than she has needed. She says after her first month of recovery she wasn't "sitting around being waited on." She knew Lionel, her husband and caregiver, had a busy schedule so she tried to do as much as she could for herself. When back-up coverage was needed, their grown son and daughter were very helpful.

Her grandchildren, to whom she has been a second mother since they were born, have been very sweet; Val recalls proudly how her 11-year-old grandson reached out to hold her arm to assist her up a hill. Val's grandchildren are a large part of why she wanted to have the transplant. To be there for them, be able to spend the extra time with them, and actually do things with them.

She says she would do it all over again; the transplant has been well worth it . . . despite the challenges that have come about as a result. Bronchoscopies have been hard on Val. She becomes extremely shaky, weak, very cold, and has even passed out afterwards. In Val's opinion, it seems to be getting worse after each bronchoscopy she has. Val has also been struggling with chronic diarrhea and she suspects mycophenolate could be the culprit. Val confirms both of these annoying issues are being discussed with her doctor in an effort to determine the root causes and possible solutions. Another new challenge for Val is clumsiness. Having been such a self-sufficient person, she finds it frustrating when she can't perform a task without knocking something over, which – according to Lionel – happens frequently

Val has this advice to give to other patients just starting on the transplant journey:

- Get strong enough to go through transplant and remain positive; positivity is a big part of it.
- Try to be supportive for other people in the lung transplant support group; everyone's journey is different.

To summarize, Val says there are no guarantees with life, but based on her experience, she feels she would have died by now if she hadn't gotten the transplant. She is content with little things; big stuff, like climbing a mountain, isn't important to her. Spending additional time with her grandchildren is.

#### FROM THE CAREGIVER'S CORNER – Lionel Flood

In the lung-transplant community, the phrase "dry run" usually bears a negative connotation. However, Lionel Flood, caregiver for his wife Valerie (Val), found her dry run to be extremely educational and enlightening. He now understands why a lung transplant is an all-day event, with the potential lung recipient checking in at 5:00 a.m., but not knowing until dinnertime whether the surgery is a "go." He wishes he'd had received more information about what to expect of the whole transplant-day process earlier. After all, not every transplant patient and caregiver get to learn from a dry run. He describes it as, "Everything happens very quickly, yet takes all day."



Lionel and Val have been together 43 years, but in their words, they are not attached at the hip. When Val's real transplant day arrived, Lionel was not sitting with her 24/7. His job allows a flexible schedule, so during the stretches of waiting, Val encouraged him to leave to take care of work-related tasks. Lionel does confess that in addition to the work commitments, he had a poker game to attend that night. As he points out, referring to the surgery, "If everything goes well, there's nothing I can do; if things go badly, there's nothing I can do." He is quick with assurances that the nurses kept him updated by phone and, of course, he couldn't concentrate on the poker game!

Val was released from the hospital in less than a month. Once home, Lionel felt as though he assumed the responsibilities of 12 to 15 hospital staffers. He found the first attempt at pill-tray set up to be very challenging due to needing to know which pill is what medication, which belongs in each compartment, and which meds are crucial to take exactly on time versus those that may allow some leeway. He acknowledges that patients are not sent home when they are not ready, but he wishes there had been more guidance regarding the state of the patient once home and in the caregiver's responsibilities. He recalls going to Val's first follow-up appointment without "the book" which caused a stir. Lionel describes the early days as baptism by fire; informational pamphlets are provided but he suggests the transplant program should implement a training class for caregivers. He has since become friends with others in the lung transplant community and has served as an unofficial mentor to other caregivers asking, "what do I do now?"

Lionel says it's been rewarding to go places and do the things they want (nothing adventurous) without dragging all the oxygen tanks along, or worrying how long the tanks will last. They feel they're able to take a few more calculated risks – for example, going out for dinner – but are cautious while doing it. He shares that Val felt like she was dying a little more each day, but that wasn't apparent until after transplant; the family was getting on with the business of dying and now they're not.

Changes that Lionel has noticed in Val are that the meds make her a little foggy-headed and she knocks over quite a few things as she reaches for something. Her attitude seems to have changed as well; previously she would have been OK with it, but she become more defensive now and gets frustrated.

Lionel has quite a bit of good, practical advice to offer to other caregivers:

- Clinic days are all-day events; need to plan to take along all meds, charts, snacks, and insulin (if needed).
- Attend the evening Caregivers Support group on the first Monday of each month and participate.
- Don't rally the troops the day after the surgery; wait until you get home, then get help from friends and family.
- Tell friends and neighbors to bring little, not big, casseroles, because the patient can't have leftovers. Or split the big casserole into small containers and freeze immediately (then they're not leftovers).
- Get a bell so the patient can summon you (Val adds, don't wear headphones).



A Message from Breathing New Life

In recognition of our mission to support the M Health Fairview lung-transplant patients with financial assistance, we are participating in the annual GiveMN – Give to the Max fundraiser on **Thursday, November 16, 2023**. Each year, generous supporters like you celebrate Give to the Max Day by making your online donation on GiveMN.org.

Your donation on Give to the Max Day may also help Breathing New Life win additional prize grants! Through November 16th, every gift made on GiveMN.org will be entered into additional prize drawings for GiveMN Golden Tickets which will be awarded as often as every 15 minutes. Your gift of \$5 or more could instantly turn into an extra \$500, \$1,000 or even \$10,000 for Breathing New Life!

The more gifts Breathing New Life generates on GiveMN.org during Give to the Max Day, the more our chances increase to receive those additional prize grants. Please spread the word, forward this message, post on social media, distribute as you see fit.

Please mark your calendar & make your gift on November 16 (or prior; early giving is now underway.) by visiting: <u>GiveMN-BNL</u>

Thank you! Breathing New Life



# **VOLUNTEER FOR BREATHING NEW LIFE**

# **Golf Committee Member Openings**

Due to the retirement of several long-term members, the BNL golf-tournament planning committee has openings for two to three new members whose primary focus will be to solicit prizes, gift baskets and donations from local businesses.

The committee will begin meeting, via Zoom, in January 2024 and will meet monthly through July.

The current 2024 Planning Committee members are:

Christel Nowling – Chairperson Deb Vreeman Susan Mason-Lommen Lisa Stackhouse

If you are interested in working with Christel, Deb, Susan, and Lisa to ensure the July 27, 2024 golf tournament is a success, please send an e-mail message with your contact information to golf@breathingnewlife.org.

## **Board Vice-President Role**

The Vice-President position on the Breathing New Life Board of Directors remains vacant at this time. The Vice-President performs the duties of the President, in the event of the absence or disability of the President.

If you have an interest in applying for the Vice-President position, know someone who may be a good candidate, or have additional questions, let us know by using any of the following methods:

- sending an email to <u>info@breathingnewlife.org</u>.
- filling out the <u>Contact Us</u> form on the BNL website and expressing your interest.
- reaching out to anyone currently on the board.

## Sign Up to be a BNL Volunteer

If you wish to be considered for volunteer opportunities when the need arises (e.g., to help at a future BNL event), add your name to our Volunteer Database so we know we can contact you.

Sign up here: Volunteer Database

# OTHER WAYS YOU CAN HELP BREATHING NEW LIFE

#### **Donate in Honor or Memory of a Transplant Patient**

If you wish to make a donation in honor or memory of a loved one whose life was touched by a lungtransplant, you may make a donation online by visiting the <u>Give MN Donation page</u> and using a credit card, PayPal, Venmo, or Giving Card.

If you prefer to donate by check, you may mail your check, made payable to Breathing New Life, to this address:

Breathing New Life 6417 Penn Ave S Ste 7 – 1210 Minneapolis, MN 55423-1196

#### Establish a Facebook Fundraiser

Commemorate a transplant anniversary or birthday by creating your own Facebook fundraiser to request donations for Breathing New Life!

If you already use Facebook, it's an easy way to encourage your friends and family to support our organization without incurring any cost to yourself. Facebook covers all fees for donations made to charitable organizations; therefore, 100% of donations come to our organization via PayPal Giving Fund.

#### Create a Breathing New Life Facebook fundraiser by following these steps:

- Choose the 💙 Fundraisers option from the menu.
  - The Fundraisers option is usually on the left side of the screen on desktop devices and laptops. It can be tricky to find on some mobile apps, but if you type "fundraisers" in the search box, you should be taken right to it, then click "+Create Fundraiser."
- Click on the big, blue button labeled, "Select Nonprofit"
- Type "Breathing New Life" into the search box and tap enter or done.
  - You may still have to scroll a bit (but not far) to find it in the list of organizations that pop up.
- Choose Breathing New Life from the list by clicking on it.
  - To ensure you have the correct organization, look for "Health and Human Service Minneapolis, MN" under our name. Be careful not to choose the church of a similar name.
- Tailor the fundraiser to your preferences by completing the following fields:
  - Amount of money you wish to raise or your goal.
  - The end date of your fundraiser.
  - Add a catchy title.
  - There is a "canned" description" but you can modify it to tell your story or make the appeal more personal.
  - Add a photo that, if you wish.
- Click the blue "Create" button.
- Once your Breathing New Life fundraiser has been created, you can share it to your newsfeed or invite specific friends . . . and don't forget to make your own donation.

## Purchase a Breathing New Life T-shirt!



Gildan SoftStyle<sup>®</sup> 100% cotton, shortsleeved, shirt with the full-color Breathing New Life logo and tagline on the front and our website address displayed on the back. Our BNL initials appear on the sleeve as well.

Shirts will be available for purchase at fundraising events (e.g., the Breakfast Fundraiser and the Golf Tournament), or by using the mail-order form below.

Breathing New Life T-shirt Order Form						
Name:						
Shipping Address:						
Phone:		E-mail:				
Size	Order Qty	Shirt Cost	Totals	Payment Methods		
Small		x \$20	\$	Credit card (provide card details in the following fields)		
Medium		x \$20	\$	Credit card #:		
Large		x \$20	\$	Exp. Date:		CVV/CVC:
X-Large		x \$20	\$	Billing Zip Code:		
2X		x \$22	\$	Check (mail complete	d forn	n & check to address below)
3Х		x \$22	\$	Shipping Charges		rdering more than three s, please send an email to
Total cost of shirts:		\$	\$7 for 1 or 2 shirts	info	<pre>@breathingnewlife.org to</pre>	
Add shipping (see chart at right):		\$	\$10 for 3 shirts		in correct shipping charges re submitting payment.	
Total amount due:		\$				

- If paying by credit card, provide your credit card information in the appropriate fields, scan the form and submit it via email to <u>info@breathingnewlife.org</u>. You also have the option of mailing the form to the address below.
- If paying by check, you must mail the form and your payment to: Breathing New Life

6417 Penn Ave S Ste 7 - 1210 Minneapolis, MN 55423-1196

# KNOW THE NONPROFITS

Within the lung transplant community, the names of various non-profits are mentioned fairly regularly. But what is each nonprofit's role in supporting lung transplantation, or organ transplantation in general? And more specifically, what are their differences? The chart below is intended to provide a summary of what each organization is all about.

Nonprofit Logo and Link	Focus	Target Demographic
LifeSource organ, eye and tissue donation Learn more at: LifeSource	<ul> <li>LifeSource, as an Organ Procurement Organization (OPO), focuses on three core services: <ol> <li>Managing all aspects of organ, eye, and tissue donation, including organ recovery and recipient matching,</li> <li>Supporting donor families, both at the hospital and after donation, and</li> <li>Educating communities and healthcare partners about their roles in the life-saving process of donation.</li> </ol> </li> </ul>	LifeSource serves the approximately 7 million people who live in communities across Minnesota, North Dakota, South Dakota, and portions of western Wisconsin. There are 55 other OPOs, each having its own designated service area.
Image: Constraint of the second se	Donate Life America (DLA) serves as a national voice to motivate, inspire and encourage the public to register as organ, eye and tissue donors. Donate Life State Teams (such as Donate Life Minnesota, Donate Life North Dakota and Donate Life South Dakota) play a vital role in DLA's work and include members of the donation and transplant community, government agencies, motor vehicle departments, hospital associations, and recipients and donor families.	Donate Life America manages the National Donate Life Registry at <u>RegisterMe.org</u> . As part of the National Registry, Donate Life Minnesota, North Dakota and South Dakota are state- based donor registry websites managed by LifeSource at <u>DonateLifeMidwest</u>
Lung Transplant FOUNDATION	<ul> <li>The Lung Transplant Foundation:</li> <li>1. Supports research into post- transplant rejection and improving long-term outcomes,</li> <li>2. Raises awareness about organ donation, and</li> <li>3. Provides education and emotional support for transplant recipients and their caregivers through their <u>Mentorship Program</u>.</li> </ul>	Based in North Carolina, the Lung Transplant Foundation is a national non-profit organization serving lung- transplant patients across the United States.

# HELPFUL RESOURCES



# FOR PATIENTS AND CAREGIVERS

The Lung Transplant Foundation (LTF) offers a peer-to-peer mentoring program which provides free, confidential & compassionate support for lung transplant patients and their caregivers.

Please be aware, LTF has recently made changes to their website; now all mentorship requests are directed through a single link. Therefore, if you wish to request a mentor <u>or</u> become a mentor, click here to begin: <u>Lung Transplant Foundation Mentorship Program</u>.

Once you are on the Mentorship page of the LTF website, select one of the following four options:

- I'm a lung transplant recipient and want to become a mentor
- I am/will be a lung transplant recipient and want to request a mentor
- I'm an experience caregiver and I want to become a mentor
- I'm a caregiver and want to request a mentor

LTF works to match mentors with transplant patients by things they have in common, such as disease, age, and transplant center.

WEBSITE LINKS	FACEBOOK GROUP LINKS
HealthWell Foundation (medication expense	<u>Minneapolis MN Lung Transplant Support Group</u>
assistance)	Lung Transplantation Taking Flight with New Life
Wilder Caregiver Support and Resources	<u>CF Lung Transplantees</u>
• <u>LifeSource</u>	<u>Alpha-1 Antitrypsin Deficiency Support</u>
<u>Alpha-1 Foundation</u>	<u>COPD Support Group</u>
<u>COPD Foundation</u>	<u>Cystic Fibrosis Community</u>
<u>Cystic Fibrosis Foundation</u>	Pulmonary Fibrosis Information by Breathe
<u>Cystic Fibrosis Research Institute</u>	<u>Support</u>
Pulmonary Fibrosis Foundation	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.

SUPPORTING **M HEALTH FAIRVIEW** LUNG TRANSPLANT PATIENTS & FAMILIES



# **PRESIDENT'S REPORT**

Welcome to Fall!

The BNL golf tournament was an amazing success again this year. Thanks so much to the planningcommittee members and event-day volunteers for the countless hours you put in to making this a wonderful experience. Also, thank you to the golfers. The golf event provides a substantial portion of the resources we need to help those on their transplant journey. We need volunteers to serve on the planning committee for the 2024 event. Please make this your year that you give back by volunteering.

BNL's new board members are digging right in and asking great questions. We spent our August board meeting discussing what we want the organization to look like in the next five years. We debated whether we should expand the group we serve. We decided it is best to stay laser focused on supporting those who are on their transplant journey at the University of Minnesota only.

The next question, which remains open, is how do we better serve those on their transplant journey? The BNL board would love to hear from you. How do you think we can better serve the lung transplant community? Are there additional services we can provide? What are the largest unmet needs. Please feel free to contact any board member with your thoughts.

It is the season where we are reminded to express our gratitude. I am appreciative of the advances in science that continue to improve the outcomes of lung transplants. Of course, no transplant would be possible without the selfless gift of donation. I am so grateful for all the donors who have made life for others possible. We thank the donors with each breath!

. Joe Stackhouse

President Breathing New Life