



HOPE CHEST NEWS

WINTER 2010

LifeSource Makes Transplantation Work In Upper Midwest

Jeff Richert, Community Advocacy Coordinator for LifeSource recently shared how they work with transplant centers. Lifesource is a non-profit organ and tissue procurement and distribution organization located in Minneapolis. It serves 200 hospitals located in the Dakotas, Minnesota and 3 counties in Western Wisconsin. There are 8 transplant centers in the region. The centers and the programs they offer are:

- Abbot Northwestern, Minneapolis—Kidney & heart

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- Hennepin County Medical Center, Minneapolis—Kidney

- Mayo Clinic, Rochester—Kidney, liver, pancreas, heart & lung

- University of Minnesota Medical Center, Fairview Min-



Jeff Richert, LifeSource

neapolis—Kidney, liver, pancreas, heart, lung, intestine & islets

- Meritcare Transplant Services, Fargo—Kidney, pancreas

- North Dakota Transplant Center—Bismarck—Kidney

- Avera McKennan Transplant Institute, Sioux Falls—Kidney, Pancreas
- Sanford Transplant Center, Sioux Falls—Kidney

Statistics provided by Jeff show that in April of 2010, there were a total of 2,893 individuals waiting for a transplant of one type or another. In 2009, there was a total of 579 organs transplanted. One donor can help up to 60 people with organ and tissue donation.

LifeSource's mission is "to provide the bridge between the loss of life and the gift of life through organ donation and transplantation". LifeSource provides a valuable service to the donor family and the recipient.

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

Hope Chest News And LifeSource

There is some confusion with transplant patients and families with regard to Hope Chest News and Lifesource. Many think they are one in the same. They are not. Both organizations provide many valuable services to transplant recipients but they are different. Lifesource is an organ distribution organization. Hope Chest News provides support and education to lung and heart/lung recipients and their families at the University of Minnesota, Fairview Hospi-

tal. The support can be financial, if needed. Other types of support include a weekly support group and a mentoring program for both pre and post transplant patients and their families. Everyone that is active in Hope Chest News is a volunteer and either a transplant recipient or family member. Many of the individuals that volunteer at Hope Chest News also volunteer with LifeSource but they are separate organizations.

President's Message

I can not remember a Fall with nicer weather and more vibrant leaf colors than this has been. We're quickly approaching Thanksgiving and then Christmas. By the time you read this, millions of turkeys will have given the ultimate measure.

Hope Chest News is like most of us. We all collect things. The Board decided it was time to have a formal storage space for all of the "things". We were able to take advantage of an offer for 1 year of free storage.

At the November Board meeting, \$3,500 was set aside to be used for Christmas debit cards for transplant patients and those waiting who might not otherwise be able to celebrate. Marget Schidlke will select the families. It was also decided to pro-



vide Thanksgiving meals for 3 families that are currently in Minneapolis post transplant.

An "atta girl" to Harriette Wock for organizing and then selling many of the Herbergers coupon books. The fundraiser brought in \$788 for Hope Chest News. An "atta boy" to Ed Aubitz for his work in researching and then finding free storage space for us.

I hope you all have a good Christmas with your friends and family and are thankful for the gift of life you have received.

Ross House

Calling All Golfers (Non-golfers Too)

If you are a golfer or just want to help Hope Chest, the Marie Anderson golf outing committee needs you big time. There are a number of opportunities to serve on the golf committee. None of the jobs require a great

deal of time or effort. If you live in the Twin Cities area, get off the couch and shut off the TV. This is a great way to help out plus you get to meet some super people. To sign on, call Ed Aubitz at 952-457-8281

Upcoming Events

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

McKenna 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 December 20, January 17, and February 21 at 12:30 P. M. in the conference room of the Bridges cafeteria at U of M Fairview.

A Hope Chest News bake and craft sale will be held on December 13th by the Outside In Cafeteria in the Phillips-Wangenstein Building.

Medicare Changes Coming



For those over 65 or with certain disabilities, there are some major changes coming in 2011 to Medicare..

- Your prescription drug costs in the doughnut hole will go down. If you have Part D prescription coverage, the doughnut hole is where coverage stops. You might be covered up to \$2,830 and then have to pay for drugs until you have spent \$4,550. In 2011, you will get a 50% discount on brand name drugs and a 7% discount on generics. You should check your Part D coverage carefully to be sure you have the correct coverage for the drugs you need.

- There will be better access to free preventative care. Starting in 2011, you will be entitled to a free preventive check up each

year.

- Your chance to change your plan during enrollment periods will change. The first is the Annual Enrollment Period that runs from November 15 to December 31. You can drop, add or change things in your plan. The other period is open enrollment and used to run from Jan. 1st to March 31st. Starting in 2011, Annual Enrollment will run from October 15 to December 7th. Open enrollment will be shortened to January 1st to February 15th.

- Premiums for Medicare Advantage plans may drop slightly in 2011. However, they are anticipated to rise in 2012 due to a drop in federal funding.

- Premiums for a traditional Medicare plan may go up. The threshold for higher premi-

(Continued on page 5)

Transplant Anniversaries October to December

152	Dennis Adams	SL	10/14/98	374	Anton Ahlhelm	SL	11/25/08
292	Ann Alexander	DL	10/28/07	153	Barbara Beck	SL	11/18/98
82	Arlen Anderson	DL	10/24/98		Ron Bergerson	SL	11/17/03
307	Ed Aubitz	SL	10/17/05	173	Mary Cordes	SL	11/01/99
61	Roger Beck	SL	10/25/93	164	Lisa Dekowski	DL	11/01/05
59	Jo Brouwer	SL	10/22/93	174	Richard Fitzgerald	SL	11/01/99
305	Judy Cannon	SL	10/09/05	310	Colleen Goodin	SL	11/04/05
14	Mack Croyle. Sr	HL	10/04/89	16	Cherry Hamlin	SL	11/05/90
100	Harold Ezzone	DL	10/25/00	177	Lester Hanson	SL	11/17/99
	Sharon Fletequal	SL	10/07/03	312	Robert Howden	SL	11/26/05
30	Mathew Gould	DL	10/16/94	224	Emma Jean Knopik	SL	11/25/01
147	Gina Hanson	DL	10/06/04	335	Brad Knutson	SL	11/03/06
220	Jane Harmon	SL	10/29/01	336	Hugh McDonald	SL	11/03/06
333	Ross House	SL	10/26/06	175	Gordon Olson	SL	11/02/99
306	Shirley Irwin	SL	10/09/05	141	Delores Opatz	SL	11/09/97
44	Terry Juezk	HL	10/12/98	311	Roger Remer	SL	11/17/05
356	Janet Klein	SL	10/31/07	334	Darlene Reynolds	SL	11/03/06
	Pamela Krake	SL	10/01/02	310	Sandra Sazama	SL	11/04/05
129	Vern Kuehnl	DL	10/05/02	53	Mary Williams	DL	11/06/96
304	Doris Oman	SL	10/05/05		Pat Chmielewski		12/01/00
1	Heather Penick	LL	10/05/00	117	Pete Conwell	DL	12/20/01
101	Kathy Rabbitt	DL	10/27/00	166	Pam Cullen	DL	12/07/05
58	Norman Rathbun	SL	10/19/93		Linda Curran	DL	12/25/02
81	Sally Reagan	DL	10/21/98	227	Dennis Dahl	SL	12/16/01
4	Allen Sorenson	LL	10/10/01	182	Bob Koziack	SL	12/17/99
51	David Swanson	DL	10/01/96		Diana Larson	SL	12/12/07
	Melissa Thomason	DL	10/30/05	106	Sandra Majeski	SL	12/19/95
43	Gaye Trcka	DL	10/29/95	314	Rose Otterstetter	SL	12/27/05
52	Ellen Varney	DL	10/26/96		James Pratt	DL	12/19/02
244	Dennis J. Weiland	SL	10/11/02	183	Pat Swirtz	SL	12/31/99
116	Hal Wenaas	DL	10/07/01	210	Natalie Szabadas	DL	12/08/08
308	Eunice Zimprich	SL	10/17/05	67	William Way	DL	12/20/97

Donations And Memorials

In Memory of Kip Peterson

Darrell & Bernice Baltzer

Roger & Janice Titus

Elizabeth Jerome

Richard & Corinne Johnson

Hal & Mary Jane Wenaas

Matthew & Elizabeth Monarski

Harriette & Mike Wock

Margarita Alvarez

Phyllis Bougeois

Eileen Vierow

Brett & Heather Abrahamson

Barb Peterson

In Memory of Dan Clay

Donald O'Brien Chelsea E. Kasai

Debra. O. Cranwell

Randy L. Anderson Hinda Litman

An anonymous memorial

Patricia Bromley Ann Fischer

Roger & Carolyn Barsness

Thomas & Beverly Osiecki

Lee & Mary Sievers Daniel Simon

Howard & Mary Swedin

Douglas & Nancy Pedersen

James & Rayanne Nelson

Pamela McDonald Geraldine Jolley

Michael Tenney

Robert & Denise Hoke Dorsey Grothe

Dale & Pamela Quam Jay & Mary Blegen

Gary & LouAnn Welfen

ECM Publishers, Inc. John Mentz

Donald O'Brien

In Honor of Ed Aubitz & Brian Frederick's 5

Year Anniversary

Mary Ruff

In Memory of Judy Murphy

Charles Ravine

In Memory of Gerald McMurphy

Hinda Litman

In Memory of Sue Saffel

Hinda Litman

In Memory of Eileen Ronning

Hinda Litman

Medicare Changes Continued

ums has been adjusted for inflation. That will no longer be the case. If you earn over \$85,000 individually or over \$170,000 for a couple more people will be paying the higher premium.

- You may have better access to primary care physicians. The new health care changes provide a 10% incentive for certain types of doctors in designated areas.

- If you're on an advantage plan, your out of pocket costs may go down. Starting in 2011, your maximum out of pocket amount can not be more than \$6,700.

As with most government plans, it can be confusing. Many drugstores, social agencies and churches have access to professionals who are able to help you understand the changes and make the right choices to fit your needs.

Gifts of Life From Our Son Lance

On June 26, 2001 our 31 year old son, Lance suffered from an aneurism in his brain. He had already accomplished a lot since June of 1988 when he had a car accident and became a quadriplegic. In spite of being paralyzed from his neck down, he earned a Bachelor of Science and a Masters Degree in Finance from U.W. Whitewater. He had various jobs including tutoring college students, being a financial adviser and working for the Wisconsin Department of Financial Institutions. He overcame many challenges through the 13 years in his sip & puff wheelchair and as parents we considered him very independent in a lot of ways. The dependent part was the need to have caregivers at college and having us as parents be caregivers at home. He influenced many friends who chose vocations in the field of special needs, physical therapy, and health care.

Lance had come through many health challenges since his accident but coming through the last one just wasn't in God's plan. As parents, we had to make the decision to let him go on July 3, 2001. Lance gave gifts of life to more than three people. On his behalf, corneas, kidneys and liver were donated.

Not sure who sent the first letters, but we sent three letters to the main recipients through the Transplant Department at U.W. Hospital in Madison. Two of the recipients sent letters to us through the hospital. Within a short time, we were given the choice to sign waivers so we could communicate directly with the recipients and they

could do the same. The third person – one who received a kidney from Lance never did connect with us. We were able to check with the hospital over the years to see how this person was doing.

The gentleman who received Lance's liver wrote or called us several times each year. With the new liver, he was able to live to see and enjoy several grandchildren born after the transplant. We had never met him in person but had sent him a photo of Lance in a closed envelope. He had a choice after reading our letter to open the sealed envelope to "meet" Lance. He chose to open it and had the photo of Lance framed and on his stereo. We did not meet him but when he passed away about two years ago, we went to the visitation and met his family. They were very grateful for Lance's gift and one of the sons now has Lance's photo as a keepsake.

A woman transplant surgeon was the recipient of one of Lance's kidneys. She also chose to write or call us directly. We have not met her, but did invite her to our daughter's wedding this past summer but she was not able to attend. She also has a photo of Lance framed by her bedside and thanks him on a daily basis for his gift. Since receiving the healthy kidney, she has had some foot surgeries and has taken up walking in some marathons in memory of Lance. She has continued helping others in need of medical services and was involved in the aftermath of Hurricane Katrina.

Through the past nine years of being without Lance, it gives us comfort to know

that he continues to “give” . He truly does live on in our hearts and the daily lives of his recipients. It is always the choice of a recipient to acknowledge the “gifts” in the way they are most comfortable. Whether the acknowledgement is in the form of a letter, e-mail, phone call or prayer, the donor and the recipient and their families know the effect

of the GIFTS. Sometimes it is hard to write the words, but the grateful thoughts are there every day.

The best of ongoing health is wished for all the recipients and endless thanks to all those who are donors.

Lance’s proud parents, Gary and Jean Frank, Gillett, Wi.

Remembering Those Gone

Sue Saffel on November 27. Sue received a double lung on May 18, 2004.

Please note, if you lose a loved one and wish to have the information in the

newsletter, you have to let us know. Email can be sent to agsector@gmail.com. Because of the large geographical area covered by the newsletter, we often have no way of knowing of your loss.

Recent Transplants

There have been 4 double lung transplants completed since the last newsletter.

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. 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 Center Profile



Dr. Jordan Dunitz is the Director of the adult cystic fibrosis program in the Transplant Center. He is Board Certified in Critical Care Medicine and Pulmonary Medicine and is an Associate Professor

in the Division of Pulmonary, Allergy, Critical

Care and Sleep Medicine at the University of Minnesota.

Dr. Dunitz is originally from a small town in New York state. He received his B.A. from Indiana University where he was inducted as a member of Phi Beta Kappa. He attended medical school at Stony Brook Health Sciences Center in the New York University system. In 1988, Dr. Dunitz came to Minnesota for his residency. He says he ex-

pected to stay for 3 years but never left.

Dr. Dunitz is married and has 2 children, a son who is a Junior in high school and a daughter who is a Sophomore at the University of California, Davis. At one point in his past, he played drums in a rock band

but hasn't played in years. He does say that if there are a couple of guitar players and somebody on bass, he would still be ready to jam. Away from the Transplant Center, he enjoys kayaking and would like to learn to sail someday.

Transplant Morsels—Bits Of Information

CF Drug to Undergo Phase 3 Study

The Cystic Fibrosis Foundation has put out information and frequently asked questions with regard to a drug currently named VX-770. It is hoped that the drug will help those

with the G551D gene mutation of CF. For more information and to read the frequently asked questions put out by the Cystic Fibrosis Foundation, go to http://www.cff.org/research/ClinicalResearch/FAQs/VX-770/#Is_VX-770_a_pill? on the web.

CF Foundation Advocacy Program

The Cystic Fibrosis Foundation has an advocacy program, Make Every Breath Count. Those that are interested can sign up on the Foundation website. Those that participate will join other advocates to meet with their

Member of Congress near their home. The program helps make a difference in the fight against CF and gives those with the disease a voice that may help promote Congressional action. To sign up, go to <http://www.cff.org/GetInvolved/Advocate/EveryBreathCount/> on the Internet.

Raising IPF Awareness

Every year, 40,000 people die from breast cancer. Every year, Idiopathic Pulmonary Fibrosis kills the same number of people, yet many have never heard of it.

Two local men with IPF had never heard of it until they were diagnosed. Now they are raising awareness and taking the fight against the disease to Capitol Hill.

Paul Fogelberg and Dan Estep are both fighting IPF. There is no cure and no known cause of this disease that attacks the lungs. Most people who get IPF die within five

years.

Both men are using their passion and expertise to fight the deadly disease, not only for themselves, but those yet to be diagnosed. They are working to get a bill passed in Congress to get funding for research and a patient registry for IPF. Already both Minnesota senators and three other members of Congress have signed on to support the bill, along with dozens of other lawmakers.

Fogelberg was just in Washington last week to meet with lawyers and lawmakers. He's hoping the upcoming congressional session

will end with the Pulmonary Fibrosis Enhancement Act passed, possibly putting him one step closer to a cure. The story can be accessed on the web at <http://kstp.com/news/stories/S1856218.shtml?cat=1>

(Source: Channel 5, KSTP)

Lacrosse Man is IPF Advocate

Dan Estep has a deadly disease that has no cure and no FDA-approved treatment. The La Crosse man has a disease that kills 40,000 Americans each year, the same number who die from breast cancer. While breast cancer has overwhelming public awareness, support and funding, Estep's disease — pulmonary fibrosis — is almost a secret, silent medical condition. Pulmonary fibrosis suffers from the lack of national focus and government-supported funding to find a cure, or at least a viable treatment, Estep said. Estep is trying to change that. He has accepted the role of a spokesman for the disease in Wisconsin. He is spreading public awareness of the disease and will go to Washington, D.C., in February to meet with lawmakers on bills pending in Congress for more education, advocacy, funding and a patient registry. "There is a silence with this disease, so I must speak out," Estep said. "A lot of people are dead three years after their diagnosis. "I feel grateful that I am not yet dead, and I feel obligated to speak for them," he said. Estep's journey with pulmonary fibrosis began with a bad cold and some congestion in January 2008. He couldn't sleep and had trouble breathing, and thought he had pneumonia. A physician ordered a chest X-ray, and Estep received a call from the doctor at 9 p.m. the same day.

The doctor wanted another X-ray. Three weeks passed, and Estep was getting better but was still coughing. A CT scan showed lung scarring. Meanwhile, he searched the Internet for possible diagnoses, and he read a blog from someone with pulmonary fibrosis describing his lungs turning to concrete. "There were five things it could have been, and I hoped for the least damaging, but it was the worst of them," he said. A surgical biopsy confirmed pulmonary fibrosis, a serious disease that causes progressive scarring of the lungs and eventually death.

His wife, Amy, an emergency medicine nurse at Gundersen Lutheran, knew it wasn't good. "Her body went limp. I tried to comfort her," Estep said. "It was like the tablecloth had been pulled from under you. I was numb." Dr. Scott Skibo, a Gundersen Lutheran pulmonary disease expert, said pulmonary fibrosis is a "grim prognosis" for his patients. Most of his patients die within three to five years after diagnosis. "All a physician can do is monitor my decline," Estep said. "I have been fortunate because my disease has progressed very gradually, more slowly than many other people." Skibo monitors Estep's lung function, which he describes as mild to moderate impairment. "It's not an uncommon diagnosis and affects so many people," Skibo said. "We see a half dozen or more new patients here every month." Skibo had a three-year fellowship at Yale University, where he conducted research on pulmonary fibrosis, looking at inflammatory responses in mice. "I think we'll have a drug some day, but it won't come easily," Skibo said. "We need appropriate funding for the disease, so we understand the disease so

we can develop a treatment.” Early detection is still important even though it cannot save a life right now, he said. If diagnosed early, patients may be eligible for clinical trials or experimental drugs. “It also gets you plugged into the transplant system,” Skibo said. “But a lot of people don’t make it to transplant.” Estep’s diagnosis wasn’t early enough to qualify for a clinical drug trial, but he was hooked up immediately with the University of Wisconsin-Madison lung transplant program. “I wanted to be plugged into the system in case I needed one,” Estep said. “But a lung transplant is not treatment, it’s a last-ditch effort to prolong my life at best.



“I’m trying to stay as healthy as I can to get a transplant if I need it, but then I also could miss the magic window of getting

one,” he said. Estep went to the Twin Cities last month to tape interviews with KSTP-TV,

which plans to broadcast a major story on pulmonary fibrosis. “It’s awe-inspiring that Dan has taken the bull by the horns and is trying to gain support and raise awareness because it’s going to take people like Dan to push forward to find a cure for this disease,” Skibo said. Estep had contacts from pulmonary fibrosis foundations shortly after diagnosis, but he wasn’t interested in advocacy. at first, I was angry. It was not a party I wanted to come to,” he said. But he changed his mind as he started to learn more about the disease. “A lot of people are dying prematurely of this disease,” Estep said. “A treatment is too late for me, but the research could benefit your children and grandchildren. “We want a chance to find a drug to arrest it, or reverse it,” he said. Estep, who will mark his 48th birthday on Nov. 18, still takes one day at a time and continues to love life. He continues to work with his passion of art, antiques and home restoration. “I don’t want to die young, but I do want to do something in my life that will benefit others, so good can come from my life,” he said. (Source: Terry Reinfleisch, Lacrosse Tribune)

American Thoracic Society Asks For Your Help

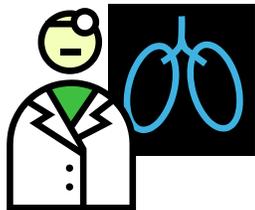
2010 is the Year of the Lung and the American Thoracic Society is asking for help. The resolution for the Year of the Lung calls for increased awareness of lung diseases such as lung cancer, COPD, asthma. Tuberculosis

and pulmonary fibrosis. You can help by calling your Representative’s office at 202-224-3121. Ask for your Representative’s office and then for his or her Health Legislative Assistant.



Drug Shows Promise For Slowing Rate of Decline In IPF

Data presented at the 16th International Colloquium on Lung and Airway Fibrosis (ICLAF) show that Boehringer Ingelheim's investigational compound BIBF1120 may provide significant benefit in patients with idiopathic pulmonary fibrosis.



Results from the Phase II TOMORROW study, presented by Professor Luca Richeldi from the Center for Rare Lung Diseases at the University of Modena and Reggio Emilia, Policlinico Hospital, Modena, Italy, show that

12 months' treatment with BIBF1120 resulted in a reduction in the rate of decline in patients with IPF.

"These results are very encouraging. Using an innovative approach to treating idiopathic pulmonary fibrosis, an effect has been shown on the primary and several other clinically relevant study endpoints. Taken together, these data provide a solid and promising platform for the development of a Phase III program." said Professor Luca Richeldi from the Center for Rare Lung Diseases at the University of Modena and Reggio Emilia, Policlinico Hospital, Modena, Italy

Hope Chest News Board of Directors And Officers

The Board members and their duties and contact information are as follows:

Ross House, President	763-593-9745
Candace Sprout, Vice Pres.	612-338-3419
Kathy Greising, Secretary	763-383-2255
Ed Aubitz, Treasurer	952-457-8281
Gary Broberg, Director	651-456-0340
Vern Jackson, Director	651-696-2962

Hinda Litman, Director	952-935-1687
Ralph Loftus, Director	763-428-3531
Sue Martin, Director	952-432-4231
Barb Peterson, Director	952-431-8442
Judy Vermeulen, Director	952-445-2497
Ellen Varney, Communications	906-524-7845

Contact any of the Board members with ideas, concerns or questions.

Who Should I Contact For

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@gmail.com

Hope Chest News

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True Dr. Stories??

A man comes into the ER and yells, “My wife’s going to have her baby in the cab.” I grabbed my stuff, rushed out to the cab, lifted the lady’s dress and began to take off her underwear. Suddenly I noticed that there were several cabs, and I was in the wrong one.

Dr. Mark MacDonald, San Antonio TX

At the beginning of my shift I placed a stethoscope on an elderly and slightly deaf female patient’s anterior chest wall. “Big breaths, I instructed. “Yes, they used to be,” she remorsefully replied.

Dr. Richard Byrnes, Seattle WA

THE FINE PRINT

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I was caring for a woman from Kentucky and asked “How’s your breakfast this morning?” “It’s very good except for the Kentucky Jelly. I can’t seem to get used to the taste,” the patient replied. I then asked to see the jelly and the woman produced a foil packet labeled “KY Jelly”.

Dr. Leonard Kransdorf, Detroit MI