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SHARING THE *gift*

A NEWSLETTER OF GIFT OF LIFE TRANSPLANT HOUSE VOLUME 1 | NO. 4 | FALL 2003

A Lesson about Waiting: Familial Amyloidosis *Submitted by Jerry Coger*

I WAS 7 WHEN MY MOTHER DIED. SHE'D BEEN SICK AS LONG AS I COULD REMEMBER. THEY CALLED IT "DROPSY" THEN. NOW WE KNOW IT AS CONGESTIVE HEART FAILURE. THIRTY YEARS LATER, MY SISTER SHOWED THE SAME SYMPTOMS. TESTING CONFIRMED A FAMILIAL FORM OF AMYLOIDOSIS.

Amyloid is a normal protein that is used and absorbed by our bodies. With amyloidosis, this protein has an altered structure so it can't decompose normally. It infiltrates muscles and organs, coats nerves, and, in our family, collects in the eyes as "floaters." In my mother's day there was no treatment, no cure. All I knew was that they died young on my mother's side of the family.

Shortly after my sister was diagnosed, my younger brother became ill. With familial amyloidosis, the liver is the main production site for amyloid. Therefore, a liver transplant was showing promise as a treatment. Both of my siblings received liver transplants in 1992. Then in 1994, I began showing signs of heart failure. Amyloidosis was confirmed, and I was immediately put on the liver transplant list in Boston where my sister lived and where amyloid research was going on. Two years went by. My heart became so weak that I could hardly walk around my yard. I went on disability from my job as a mechanic for an oil company. I lost weight. Finally my name came up to third on the list, but by then my heart was too weak to survive the surgery. Now, I needed two organs, a heart and a liver. We were devastated. Worse yet, our chosen hospital couldn't do this double organ transplant. So they sent us to Mayo Clinic.



Tricia and Jerry Coger

GETTING THE REFERRAL TO MAYO

In November 1996, my wife Tricia and I drove to Rochester. At the Transplant House, we found a whole new world of people going through the same things. What a relief! During our second week there, I developed a cough and couldn't sleep at night. I thought I'd caught a cold, but my heart was failing. I had a heart attack that night in the hospital. There was no going home from that point on without a transplant.

For the next three months, Saint Marys Hospital was home; there was no life other than the wait. My wife stayed at Gift of Life when she wasn't home with our 12- and 16-year-old children. They came to see me at the holidays, and the hardest thing I've ever done was to watch them go. If it weren't for the care of some wonderful nurses, I might have given up hope.

Four different times that winter I was told organs were available only to be disappointed. A friend sent me a shirt that I wore with pride. It said: "He who waits upon the Lord shall renew his strength" (Isaiah 40:31). Clearly, God was showing me how to wait.

continued on back page

What a "WOW" Golf Tournament Day!

From the new renovations at Rochester Golf & Country Club to the incredible speaker, this year's benefit golf tournament July 7th was a hole-in-one! More than 100 people golfed and better than 200 people enjoyed a truly inspirational presentation by Ed Hearn, of the 1986 World Series winning New York Mets. The weather cooperated fully despite many ominous clouds. (Our thanks to Sister Margeen for her powerful "good weather" prayers!)

The five fundraisers we hosted this summer to help our operating budget were each successful! What? You thought the day was all about golf? Close, but

not quite. We hosted a silent auction after the golf tournament with donated gifts as varied as an eight-carat amethyst pendant, a smoker/grill, a hotel package, a beautiful hand-made quilt, Mary Kay products, and four top-notch tickets to a Minnesota Timberwolves game. In addition, we hosted a raffle for two American Airlines tickets; the afternoon of golf; dinner and presentation by Ed Hearn; and Tribute opportunities to honor your loved one(s). Our thanks to each person who contributed to this smashing event!



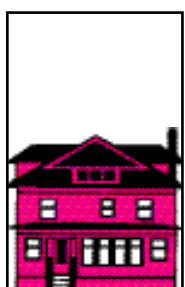
Ed Hearn holds the crowd's attention



A Mayo Pharmacy group ready to go



Eileen (an office volunteer) and Bill Harreld and their award-winning smiles



President's letter

Hello... my name is Ron Kreinbring. I was honored in May to be elected President of the Board of Directors of Gift of Life. It is an extreme pleasure to serve with the support of our excellent staff and other loyal Board Members. We feel strongly about our mission to continue to provide the loving hospitality many of you have witnessed during your stay in our home.

Summer brings many happenings at the House. Our golf tournament was a great success bringing more than 100 golfers to the Rochester Golf & Country Club. Sister Margeen had volunteered to bring us good weather for the golfers, and she came through with a wonderful day. The evening was capped by an excellent banquet and dinner attended by more than 200 people. This is a very important fundraiser for our annual budget. Much of the success can be attributed to the many volunteers, staff members, and Board Members who gave countless hours to organize this event.



Due to some generous donations, we also have begun work to beautify some of our exterior grounds. Under Sister Jane's direction, we are working on the east side of the house around the patio and on the southwest side by the Peace and Healing Garden. We hope these improvements will provide attractive and restful areas for our guests to pass the summer days remaining and the glorious fall days to come.

On behalf of the Board of Directors, staff, and volunteers, I hope you have had a wonderful summer and that you and your loved ones will enjoy a healthy and happy season of love and prosperity.

Sincerely,
Ron Kreinbring, President
Gift of Life, Inc. Board of Directors

AMYLOIDOSIS: A PRIMER

Submitted by Roshini Sarah Abraham, Ph.D., Division of Hematology, Mayo Clinic Rochester*

Amyloidoses (singular – amyloidosis) are a group of diseases that results from abnormal protein accumulation in a variety of body organs. The clinical manifestations of the disease are directly related to the organs affected by the amyloid deposition.

The term “amyloid” was coined by a Russian physician; it means “containing a ‘starchy’ substance.” There are several major and rare types of amyloidosis. However, since amyloid patients at Gift of Life Transplant House fall mainly into just two categories, this article will focus on primary systemic amyloidosis (now more accurately known as AL or light chain amyloidosis), and familial amyloidosis.

Primary Systemic Amyloidosis (AL)

Though AL is the most common systemic form of amyloidosis in the United States, it is a rare disease affecting only eight people per million per year. It also is the only amyloidosis associated with a bone marrow (hematology) disorder. In AL, one of the component cells of the immune system within the bone marrow produces a protein (which normally helps fight infections). This cell (B cell or plasma cell) starts growing abnormally and producing a variant of the original protein, which results in amyloid. The organs affected by AL include kidney, heart, liver, neuropathy (related to nerve damage), gastrointestinal, skin, tongue, and blood vessels. Some of the clinical symptoms are shared with other amyloidoses, including the familial transthyretin (TTR) amyloid and a number of other diseases. For this reason, accurate and early diagnosis of AL can pose a challenge.

The current measures of treatment for AL include chemotherapy (the most common being dexamethasone, thalidomide, melphalan, and prednisone, among others) and organ transplantation with or without autologous (self) stem cell transplantation. The goal

of stem cell transplantation in AL is to remove the abnormal immune system cells that make the amyloid protein.

Familial or hereditary amyloidosis (ATTR)

ATTR is the only type of amyloidosis that is inherited. It is a rare form of amyloidosis and is found in families of nearly every ethnic background. The amyloid in this disease is formed from the transthyretin (TTR) protein, which is made in the liver. The most common areas of the body affected are the nervous system, gastrointestinal tract, heart, and kidney. Each family has its own pattern of organ involvement and associated symptoms. The mode of transmission is autosomal dominant, which means that if you have this type of amyloidosis, each of your children has a fifty percent chance of inheriting this disease. If your child does not inherit the gene, he/she cannot pass it to future generations. The major form of therapy for ATTR is liver transplantation, since the liver produces the abnormal protein. If other organs are affected by TTR amyloid deposition, a heart and/or kidney transplant is a treatment option.

The Amyloid Clinic and Research Program at Mayo Clinic

The Mayo Amyloid Clinic, which is part of the Division of Hematology, is one of the largest in the country. Annually, we see approximately 130-140 new AL patients. Patients with familial amyloidosis also are treated through the Amyloid Clinic. In addition to the clinical treatments, staff throughout Mayo is undertaking research in AL and other amyloidoses. Research is critical to improve our knowledge of the disease process, which would allow development of more effective therapy. It also would facilitate early diagnosis, with the goal of reducing mortality and eventually preventing occurrence of the disease.

*Gift of Life Transplant House and Mayo Clinic, though separate entities, are proud to work as complementary businesses to help our mutual patients.

It's All in the Name: PBSCT vs. BMT

When discussing blood and marrow transplantation, the terms “stem cell” and “bone marrow” often are used synonymously. Although that's not a completely accurate interchange, it's not incorrect. Stem cells can be collected from peripheral blood (thus the reference: PBST) and from bone marrow. The difference in the cells is the level of maturation, or the age of the cells. Once the bone marrow stem cells have matured, they are found in the peripheral blood. How the cells are obtained also is different: from the blood or directly from the bone marrow space. PBSCs are collected through a process called apheresis, after the bone marrow has been “fertilized” or stimulated. Bone marrow stem cells are harvested in the operating room with the patient under general anesthesia.

celebrate 20!

Big Plans for a Big Celebration!

Despite the heat of summer, our thoughts have turned to that flip of the calendar on December 31st and the celebration (or celebrations!) we have in mind for our 20th anniversary. Meetings are being held, and brains are storming. **Stay tuned!**

What a Quilt It Will Be

One of our favorite phrases is “a house in which we share hope.” And there couldn't be a better representation of that than the fabulous quilt full of house images we're preparing for our 20th anniversary. Thank you to the 65 quilters who agreed to make blocks. The deadline is August 31, 2003, so please mail those blocks ASAP to “House Quilt,” c/o 2603 Institute Road, Rochester, MN 55902. We're excited to begin assembly!

WISH LIST

FALL NEEDS

- Pouches of baby wipes
- Paper towels
- Wrapped canned soups
- Liquid dishwashing detergent
- Air freshening spray for home
- Small bottles of hand sanitizer
- Toilet paper
- Postcard stamps for collection

All of these are current needs of the House.
Please help if you can! Thank you!

Primary Amyloidosis Prompts Heart and Kidney Transplants

Submitted by Sue Seiler

I had always been blessed with good health. I exercised, ate right, and lived a healthy lifestyle. That's why everyone was so surprised when I suddenly started to experience symptoms that resembled congestive heart failure. The local doctors ran many tests and tried different medications, but my condition continued to deteriorate rapidly. They knew something was seriously wrong, but they couldn't come up with a diagnosis. They decided on one last test before sending me for a second opinion. During that test I went into cardiac arrest, ended up on life support, and was air-lifted to Mayo Clinic.

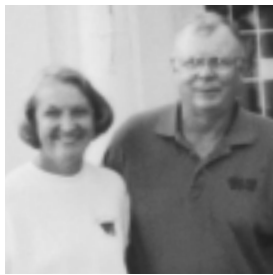
At Saint Marys Hospital in Rochester, I was stabilized and diagnosed with primary amyloidosis. It is a rare disease of the bone marrow where abnormal proteins build up and deposit in the major organs or other systems in your body. In my case it was my heart. I was told that I needed a heart transplant as soon as possible.

My husband, Larry, and I were completely overwhelmed and unprepared for something this serious. We relied on the Mayo staff to educate us about the disease and the best course for recovery, which was a heart transplant followed by a stem cell/bone marrow transplant. At this point, the support of my husband and family was what gave me the courage to face the challenges ahead. My faith in God gave me the peace to wait patiently, knowing it was all in His hands, and He would supply me with the ability to cope with it all. He did.

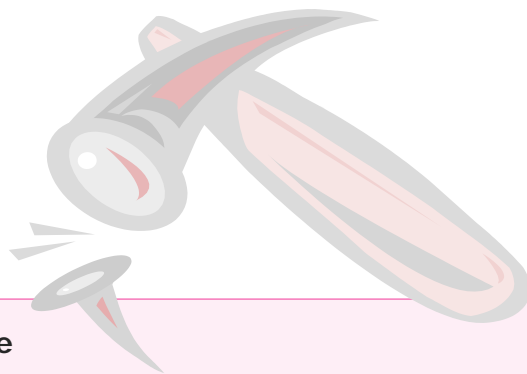
I waited two months in the ICU for my heart. May 24, 2000, was a glorious day! The recovery went well with no complications. Six months later I returned for the stem cell/bone marrow transplant. Surprisingly, this procedure was much more taxing than the heart transplant! It took longer for me to get my strength back, but it was worth it to be told in the spring of 2002 that the disease was under control. They found no amyloids in my system!

The winter of 2002 brought more to deal with, however. My kidneys began to fail, and I was informed that I needed a kidney transplant. The doctors wanted me to find a living donor since the waiting list was three to five years. My family was generous with offers, but my brother was convinced that he'd be the one. He truly wanted to give me a better quality of life. Amazingly, he turned out to be a perfect match! The transplant was done on May 14, 2002, and it was successful. We are both doing well. What a hero my brother is to me!

There are so many factors involved in recovery. It is hard work, both physically and emotionally. The strength of your faith, the support of family and friends, the high quality and compassion of the medical staff are vital. But I have to say that Gift of Life Transplant House, its staff, and the friends we met there were the heart of my recovery. It was with the people at Gift of Life that my husband and I lived day to day — sharing each other's highs and lows, supporting and encouraging each other, and becoming a unique family so far away from our own loved ones. It is a haven for both the patient and the caregiver. Larry and I are both so grateful for that experience!



Sue and Larry Seiler



Renovations Continue

As may be expected, when you own a building as large as ours, with 48 guest rooms and dozens of other rooms, watchful eyes and regular maintenance are vital. For the past several months, the bathrooms of the north wing, built in 1995 just after our purchase of the Judd house, have been getting some attention. To date, in half of the 30 units we have installed new handicapped showers, flooring, and toilet accessories, and created a better layout to make the rooms more accessible for all guests. Recent residents of these rooms have given us very positive feedback. Many thanks to those who have contributed to this renovation project!

STAFF PROFILE:

SISTER JANE FRANCES GREGOIRE,
O.S.F.

Would you believe Sister Jane Frances used to teach 7th and 8th grade English and literature? It's true. Her 32-year career as a facility manager began after she spent ten years as a teacher. A Sister since 1957, her second career began in 1971 when she went to serve at her order's New York Motherhouse as an administrative services director. While there for 20 years, she managed areas as diverse as the 135-acre grounds, the switchboard, maintenance, dietary, and housekeeping. She earned certifications in boiler operations, asbestos handling, and EPA inspections! (We're not sure which is more difficult, teenage kids or asbestos, but that's fodder for another article anyway.)

One of nine children born in Buffalo, New York, Sister Jane is quick to explain what drew her to working for our House: her only sister died at age 24 of leukemia, and Sister Jane herself is a breast-cancer survivor of 15 years. First-hand knowledge of how a life-threatening disease affects the patient and the family prompted her to reach out to others. In fact, over the 20 years she lived in New York, Sister Jane donated platelets via plasmapheresis 560 times! Sister Jane balances her time at our House with volunteer work, including a Board of Directors position at Integrative Therapies, a holistic spiritual healing center housed at the headquarters for the Sisters of Saint Francis in Rochester.

With Sister Jane's position at Gift of Life, held since 1991, she combines her talents and experiences with her passion to help people. We simply would not have such a welcoming home, a beautiful building, or awe-inspiring grounds without her!



Sister Jane Frances
Gregoire

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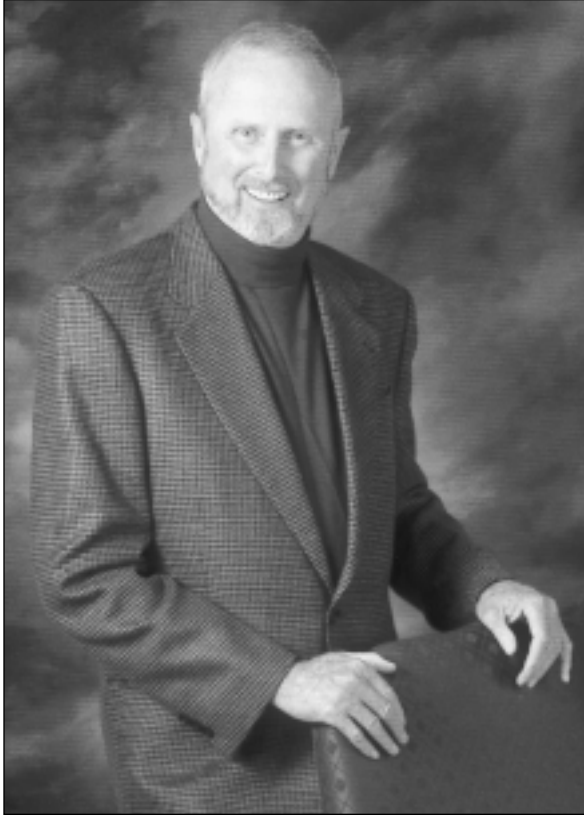
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In Memory of a Dear Friend: **Norman L. Gillette Jr.**



Norman L. Gillette Jr.

TOO OFTEN IN OUR HOME, we are given pause to reflect on the life and death of some very dear people. We reflect on the time and riches they enjoyed thanks to an organ, bone marrow, or stem cell transplant. And always, we reflect on what they have shared with us æ their struggles and joys, their courage, their tears, and their laughter. This spring, we shed tears again for many friends, each one a beloved member of our “Gift of Life family.” Among them was a gentleman who never lived here. Norman L. Gillette Jr, a long-standing businessman in Rochester, was our Board Member, our benefactor, and our friend. As is each member of our family, Norm is greatly missed.

NORM DIED MAY 20, 2003, from complications of pancreatic cancer. His death came 35 years after he received the gift of life, a kidney, from his sister, Norma. Norm was among the first successful kidney transplant recipients at Mayo Clinic, and it was during his treatment there that he met Ed Pompeian, Gift of Life’s founder. They became for each other the brother neither had. Norm’s successes in business allowed him to be generous when Ed was launching Gift of Life. And were it not for Norm’s quiet gifting, we likely would not be in the beautiful home we offer our guests today.

NORM KNEW HOW GRAVE HIS HEALTH WAS, and he ensured that his loved ones would be well cared for. Last fall, he informed the executives and Board of Directors at Gift of Life that he was making a generous donation to the House. And, though he’d always been one to gift quietly, he allowed us to host a gala reception for him on December 13th. We dedicated the west wing (built in 2000) to him. Among the invitees were Norm’s family, our Board of Directors and staff, current House guests, and dozens of mutual friends, including many Mayo Clinic personnel who have worked with Ed and Norm on various endeavors over the years.

PASTOR GARY E. BENSON of Zumbro Lutheran Church, Rochester, spoke eloquently of Norm’s generosity and of the mission of the House. He closed his comments by quoting Mother Teresa of Calcutta, who said, “May your life be something beautiful for God.” The Pastor added, “Specifically this day we recognize Norm Gillette for the expression of resources shared. And even more so, we recognize the spirit of your love and compassion shone through such a gift. ...Indeed, Norm, your life is something beautiful for God!”

IN ADDITION TO HIS INCREDIBLE GENEROSITY to Gift of Life, he established the Norma J. Vinger Center for Breast Care at Gundersen Lutheran Hospital in La Crosse, Wisconsin. This was done to honor his sister, a breast cancer survivor, and to thank her for donating her kidney to him in 1968.

NORM IS SURVIVED by two daughters and one son, seven grandchildren, his sister and her family, and many very special friends. His children have expressed a desire to be involved in Gift of Life’s activities, and we look forward to that. We are honored to be counted among the Gillette family friends. And we are pleased to have daily reminders of Norm in our home, *truly a home that helps and heals.*

A LESSON continued from page one

FIVE YEARS AFTER DIAGNOSIS

One cold February night, Tricia had just gone home (to Gift of Life) when my nurse came in with news that would change my life. I had a donor. Tricia came back, and we prayed for the family who had lost their loved one. Then on the morning of February 8, 1997, I received the gift of a donated heart and liver. I remember waking up and feeling warm for the first time in a long, long time.

Recovery wasn’t easy. I had a rejection that immediately sent me back into surgery. I had to practice walking and climbing stairs again. Four months after I walked into Saint Marys, I went “home” to the Transplant House. For the next

year I spent more time at Gift of Life than I spent at home. As I healed from one problem, something else would go wrong. It was a very low time for me, but I always had faith that I would get better. I was treated for depression during that year, and that helped tremendously. I continued my therapy and slowly started to get better.

LIFE SINCE MY TRANSPLANTS

About this time, I met the parents of my donor. Through all the hugs and tears, we learned how these precious gifts came to me. We continue to stay in touch today. As I write this, more than six years have passed. I have few limitations

now. I received a medical retirement from my job, so I spend most of my time volunteering, including speaking to groups about organ and tissue donation. Life is something I enjoy in a way I never could have before.

Did my amyloid go away? No. The protein still causes pain and neuropathy; I probably always will have eye problems. Yet, I’ve watched my children grow up and get a good start in life, and I plan to see much more. I’ve learned a few things on this journey: life is a wonderful gift. Do what you have to do each day, and let the Lord guide you to the next day. And NEVER, EVER GIVE UP!

GIFT OF LIFE TRANSPLANT HOUSE MISSION STATEMENT

The Gift of Life Transplant House mission is to provide transplant patients and their caregivers with high quality, affordable accommodations in a supportive, home-like environment.



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