MAYO CLINIC
Cancer Center

together

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Working Together to Advance Multiple Myeloma Treatment

By Kelli Fee-Schroeder

Michael Tuohy, husband and father of two, was diagnosed with multiple myeloma at 36. Like many people, Michael had never heard of multiple myeloma.

Multiple myeloma is a cancer of the plasma cells, which is a type of white blood cell present in the bone marrow — the soft, blood-producing tissue in the center of most bones. The disease is called multiple myeloma because these abnormal plasma cells can occur in multiple bone marrow sites in the body, leading to soft spots in the bone where tissue has been damaged and weakened, resulting in pain and an increased risk for fractures. In addition, as the myeloma cells crowd out normal cells in the bone marrow, the production of normal blood cells is affected. This process can cause anemia, prevent normal blood clotting, and interfere with the body's immune system which can lead to infection or kidney failure.

Although Michael was young when he was diagnosed, multiple myeloma most commonly occurs after age 50, with 71 being the average diagnosis age. After non-Hodgkin's lymphoma, multiple myeloma is the second most common blood cancer, accounting for around 1 percent of all cancers.

The exact cause of the disease is unknown, but doctors know that multiple myeloma begins with one abnormal cell in the bone marrow that multiplies. Researchers have also discovered that many myeloma cells are missing all or part of one chromosome. Studies have examined potential risk factors including family history, immune function, lifestyle, diet, and occupational and environmental influences; however, findings are inconsistent and further research is needed in this area.

While there is no cure for multiple myeloma, new research is leading to the development of earlier diagnostic tools and more effective treatments. In 2005, three leaders in myeloma genetics at Mayo Clinic Arizona came together to address the need for new treatments.

"Our goal is to deliver individualized care based on the latest genomic information and drugs available," says Lief Bergsagel, M.D., one of the lead investigators in Mayo Clinic's Multiple Myeloma Research Program. "We intend to find ways to offer the right drug to the right patient each time. And we're set to be among the first to make it happen for patients with multiple myeloma."

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On tour for the International Myeloma Foundation, Ally, Robin, Michael, and Mikey Tuohy pause for a quick pose at Mayo Clinic Rochester before heading to Colorado.

Family Road Trip Shows Cancer is Not the End of the Road

During their first cross-country trip to raise awareness of multiple myeloma, survivor Michael Tuohy — along with his wife Robin and their two children, 14-year-old Ally and 9-year-old Mikey — set forth in the multiple myeloma mobile and toured the country in summer 2007 to "empower" and encourage patients and their families. They shared that although blood cancers such as myeloma are being diagnosed in increasing numbers, new therapeutics are helping make the disease more treatable and manageable.

Traveling on behalf of the International Myeloma Foundation, the family's agenda included informational presentations, public signing of the mobile, and survivor meet and greet sessions at Mayo Clinic Rochester on June 26, 2007, and at Mayo Clinic Arizona on July 23, 2007.

For more information, contact the International Myeloma Foundation at (800) 452-CURE or http://myeloma.org.

In addition to Dr. Bergsagel, Rafael Fonseca, M.D., and Keith Stewart, M .B.Ch.B., (the United Kingdom equivalent of M.D.) are members of this research team, whose collaboration has been instrumental in a series of discoveries that are helping to reveal:

- Genetic changes that initiate multiple myeloma
- Therapies that target myeloma's genetic abnormalities to stop cancer growth
- Tailoring drug treatments to increase their effectiveness and minimize side effects

In September 2003, Mayo Clinic Cancer Center — in collaboration with Dana Farber Cancer Institute in Boston Mass. — was awarded $2.7 million as part of a multiple myeloma SPORE (Specialized Programs of Research Excellence) grant from the National Institutes of Health. This grant supports basic and clinical research for five years, focusing on translational science, or moving laboratory findings into clinical application. Drs. Bergsagel, Fonseca and Stewart have pooled their resources with Mayo Clinic Cancer Center colleagues to study the reactions between various drugs and the genes that control cellular growth, thus helping better understand and predict an individual's response to therapy.

Glenn Lyden signs the multiple myeloma mobile in honor of his father-in-law, Skip, an 8-year survivor.

Earlier this year, Vincent Rajkumar, M.D., led a study by the Eastern Cooperative Oncology Group (ECOG), supported by the National Cancer Institute (NCI), that compared combination treatment of Lenalidomide and either high- or low-dose dexamethasone. The low-dose dexamethasone combination showed a 96.5 percent overall one- year survival rate with less side effects than the high-dose combination, which had a one-year survival rate of 86 percent.

"This is the best one-year survival data that I've seen in a large Phase III study in myeloma," says Dr. Rajkumar. "This is a major advance in the treatment of cancer."

Although treatment for myeloma is tailored to each individual, standard options may include:

- Chemotherapy
- Corticosteroids
- Radiation therapy
- Stem cell transplant
- Targeted Therapies
  - Thalidomide (Thalomid)
  - Bortezomib (Velcade)
  - Lenalidomide (Revlimid)

Treatment regimens may also be recommended based on the goals of the therapy, which may include eliminating all evidence of disease, controlling disease activity to prevent damage to other organs, preserving normal performance and quality of life, providing pain relief or managing other symptoms, or managing myeloma that is in long term remission.

It has been seven years since Michael's multiple myeloma diagnosis. He initially went through a stem cell transplant after the myeloma was stabilized. In 2005, after two and a half years of remission, however, his myeloma became active again. Michael then received other drug therapies and participated in a clinical trial for Revlimid. Now, at 42, he has been in remission since spring 2006 and is active with the International Myeloma Foundation and coaches his son's Little League team. "I don't take a millisecond of life for granted," he says.

For more information on multiple myeloma, including clinical trials, visit www.mayoclinic.com, www.mayoclinic.org, or contact the Multiple Myeloma Research Foundation at (203) 229-0464 or www.multiplemyeloma.org.

Kelli Fee-Schroeder, B.S.N., R.N., is a nurse educator for the Cancer Education Program at Mayo Clinic Rochester.

Furry Friends Offer Therapy to Patients

By Dori Weisbrod

A young girl plays with Buster at Kids Kamp, a camp sponsored by FaCT and the Angel Foundation for children who have a family member affected with cancer.

The bond between dog and human is well-known and established in history. One of the most recent discoveries in this area relates to how a dog can affect our emotional well-being. Studies have shown that a person holding or petting an animal will experience a lowering of blood pressure and a release of tension. Cuddling animals can help bring a person out of loneliness and depression. Thus, the concept behind Pet Therapy.

Therapy Dogs International (TDI) was founded in 1976 by Elaine Smith, an American registered nurse working in England, who observed the benefits of pets interacting with patients. Upon returning to the United States, Elaine was determined to bring the concept of pet therapy to health care facilities. TDI is responsible for certifying, insuring, and registering volunteer therapy dogs. All dogs must pass a behavioral exam along with their handler in order to be certified by TDI.

The purpose of therapy dog visits is to provide comfort, joy, and encouragement. As a dietitian working in a nursing home, I witnessed Alzheimer's residents who were often emotionless or sad. When therapy dogs came in, these residents would spring to life. Smiling, they would reach out to stroke a dog's silky soft coat. One resident, who rarely, if ever, spoke, would sing to the dogs that visited her. These wonderful creatures were able to reach our residents and truly touch them in a way that we as trained caregivers never could. It was amazing. I promised myself that if I ever got a dog, this is what I would do.

Because of the joy that I saw TDI bringing to people's lives, I eventually got a dog. Buster, a four-year-old Boxer, who I certified as a therapy dog through TDI, works primarily with a program called Families Facing Cancer Together (FaCT). In a recent newsletter published by the Angel Foundation in Minneapolis, Minn., FaCT and the Angel Foundation announced the "Buster Fan Club." The following is an excerpt about Buster:

Seen here, Buster poses for his Birthday Club card, which is sent to children on their birthdays.

"Sometimes, when a parent has cancer and is going through treatment, he or she may be too ill, too fatigued, or too sensitive to the touch to hold a child or play and interact as much as the parent and child would like. This can make a child feel sad or rejected, and can make a parent feel sad as well. The cancer journey creates a lot of worry for everyone in the family. Buster is a great listener and we know he can sense these difficult feelings. He is very receptive to running, playing, shaking hands, rolling around, and receiving lots of hugs. Buster has brought immense joy to the children, and through his patience and charisma, has a way of reassuring the children that their parents' love, like his, is unconditional."

There are many ways that therapy dogs and other animals like Buster help their human companions. Therapy animals like Buster visit hospitals, nursing homes, schools and libraries. They elevate the mood of the patients and staff that they visit, but most importantly, offer them companionship.

To learn more about TDI or how to arrange a TDI visit to your facility, visit www.TDI-dog.org. The "Heath Care Facilities" tab includes information to request a visit from one of these amazing creatures.

Buster's owner, Dori Weisbrod, is a Therapy Dogs International certified handler who volunteers anywhere a K9 companion is needed to "paws a while for love."

Pushing Cancer Back

Transforming a Devastating Diagnosis into a Source of Strength

By Nicole Bennett Engler

Pam says that her cancer exerience taught her an important lesson: to live each day to its fullest.

Pam Moffitt never would have imagined that her chronic sinus infection could be a cancer diagnosis. After visiting Mayo Clinic in September 2003, several tests confirmed that she had an 8 centimeter tumor (the size of a large lemon) on her left lung.

When Anh-Quan Nguyen, M.D., a pulmonary and critical care physician at Mayo Clinic Rochester, told Pam to prepare for a potential cancer diagnosis, she tried convincing herself that it was anything but. "The human mind can think of so many less serious illnesses, and that's the hope that you hold onto," says Pam.

She returned home to Sioux Rapids, Iowa, to hope for the best.

But two days later in early October, when Pam, her husband, Norm, and her daughter, Tami, returned to Mayo to receive the test results, Pam learned that she had stage III squamous cell carcinoma, a type of non-small cell lung cancer in which malignant (cancer) cells form in the tissues of the lung.

"I was absolutely devastated," she says. "Having been a smoker for most of my life but quitting three years prior, those words were still hard to hear."

Pam knew that the road ahead was going to be rocky, but she was prepared to take on the disease — no matter what she had to do.

In mid-October, Pam had mediastinal surgery to remove lymph nodes in her chest and beneath the breast bone.

Two weeks later, Tami drove Pam to her first three rounds of treatment at the local oncology clinic at Buena Vista Regional Medical Center in Storm Lake, Iowa. She optimistically told her mother, "Today we start killing cancer cells!"

For Pam, that sentence was a defining moment — one during which she remembers realizing that she could fight this disease.

"I knew that I had five reasons for living, which were my five grandchildren," she says. "I was not going to give up easily without a fight. I was bound and determined to see them grow up."

Over the next few months, Pam's life was consumed with numerous tests and procedures, including blood draws which became weekly rituals. In addition, Pam underwent thoracic surgery, 32 consecutive rounds of radiation — which she jokingly calls her most expensive doctor-approved sunburn — and three consecutive rounds of chemotherapy.

Quoting her Mayo Clinic Rochester Pulmonologist James Jett, M.D., Pam reiterates that "no one deserves cancer." She says her entire Mayo medical team did a wonderful job of helping her get her mind off her diagnosis. "I am so thankful that I chose Mayo because everyone I encountered — from the janitors to the surgeons — was caring, compassionate, and helpful."

Pam reminds patients not to blame themselves for a cancer diagnosis. In addition, she recommends that patients take charge of their own health by paying attention to symptoms, questioning anything that they do not understand, and asking about clinical trials.

Looking back at her cancer experience, Pam says that it prompted her to become a passionate patient advocate dedicated to promoting the prevention and early detection of lung cancer.

When the co-chair of the North Central Cancer Treatment Group (NCCTG) — a national clinical research group sponsored by the National Cancer Institute — later asked Dr. Jett if he knew of a lung cancer patient advocate, he immediately recommended Pam. She says that gesture changed her life.

Pam Moffit, lung cancer survivor, thanks her family — including her husband Norm — and her medical team for helping her through her cancer experience.

She is now the NCCTG lung cancer patient liaison; vice president of Lung Cancer Circle of Hope, a non-profit lung cancer organization; conducts peer reviews of Mayo Clinic lung cancer clinical trial protocols; is a Food and Drug Administration patient consultant for lung cancer drugs; reviews pamphlets for publication by professional organizations; belongs to several lung cancer organizations; and travels to cancer conferences, including the Lance Armstrong Presidential Cancer Forum in Cedar Rapids, Iowa.

"It still amazes me that doctors and other professionals in this field actually remember my name and thank me for my input — me, a 60-year-old wife, mother and grandmother from a town of 720."

In addition to becoming an active patient advocate, Pam says that an important outcome of her cancer experience was the rediscovery of her faith, which she says has become an important source of strength. She also re-connected with her family and friends, and values the closeness that they have as a result.

"I often tell them that I love them," says Pam. "I want them to know that because life is too short not to express your love."

Beyond her faith, family and friends, Pam says that she inherited her inner strength from her late father. "I think I inherited this streak of don't push me unless you want to be pushed back. And that's exactly what I am doing — I'm pushing cancer back!"

As a result of this life-changing experience, Pam says that her priorities have also changed. "I've tried things I've never done before," she says. "Life isn't as scary as it once was. I choose how to live life rather than letting cancer dictate my life."

Lung Cancer Risk Factors

A number of factors may increase your risk of lung cancer. Some risk factors can be controlled, for instance, by choosing not to smoke or quitting smoking. And other factors can't be controlled, such as your sex. Risk factors for lung cancer include:

- Smoking
- Your sex
- Exposure to secondhand smoke
- Exposure to radon gas
- Exposure to asbestos and other chemicals
- Family history of lung cancer
- Excessive alcohol use

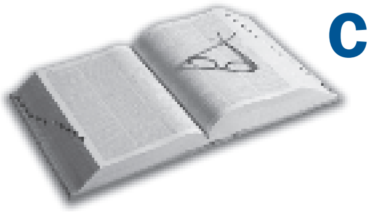
Lung Cancer Signs and Symptoms

Lung cancer typically does not cause signs and symptoms in its earliest stages, but rather when the disease is advanced. Signs and symptoms of lung cancer may include:

- A new cough that does not go away
- Changes in a chronic cough
- Coughing up blood, even a small amount
- Shortness of breath
- Chest pain
- Wheezing
- Hoarseness

For more information, visit www.mayoclinic.com or call (800) 4CANCER.

Nicole Bennett Engler is a communications consultant for the Cancer Education Program at Mayo Clinic Rochester.



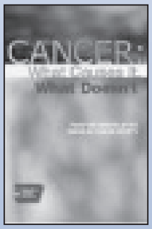
Cancer Terms

Bone marrow	The soft, sponge-like tissue in the center of most bones. It produces white blood cells, red blood cells, and platelets.
Corticosteroids	A group of synthetic hormones called“steroids,” which include prednisone, prednisolone, methylprednisolone and dexamethasone. They can be used in the treatment of blood cancers or for the management of some of the complications of cancer and its treatment.
Mediastinum	The area between the lungs. The organs in this area include the heart and its large blood vessels, the trachea, the esophagus, the bronchi, and lymph nodes.
Non-small cell lung cancer	The three main types of non-small cell lung cancer are squamous cell carcinoma, large cell carcinoma, and adenocarcinoma. Non-small cell lung cancer is the most common kind of lung cancer.
Squamous cell cancer	Cancer that begins in squamous cells. Squamous cells are found in the tissues that form the surface of the skin, the lining of the hollow organs of the body (such as the bladder, kidney, and uterus), and the passages of the respiratory and digestive tracts.
Stem cell	A cell from which other types of cells develop. Blood cells develop from blood-forming stem cells.
Stem cell transplant	A method of replacing immature blood-forming cells that were destroyed by cancer treatment. The stem cells are given to the person after treatment to help the bone marrow recover and continue producing healthy blood cells.

Definitions obtained from www.cancer.gov.

Resources

100 Questions & Answers about Myeloma
by Asad Bashey, M.D., Ph.D. & James W. Huston



Cancer: What Causes it, What Doesn't
from the Experts at the American Cancer Society

Cancer Survival Toolbox by the National Coalition for Cancer Survivorship (NCCS)
http://www.cancersurvivaltoolbox.org • (301) 650-9127

The Cancer Survival Toolbox is a free, self-learning audio program developed by leading cancer organizations to help individuals develop important skills to better meet and understand the challenges of their illness.

The goal of the toolbox is to help individuals develop practical tools for daily life as they deal with a cancer diagnosis and its treatment. Family members and caregivers can also use the toolbox on behalf of a child or anyone else with cancer.

The toolbox includes ten lessons which cover basic skills that can help individuals with cancer meet the challenges of their illness or address specific aspects of cancer survivorship including:

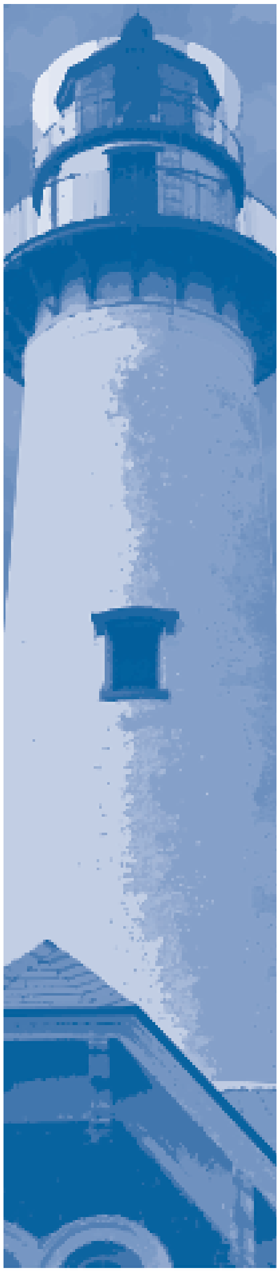
- Communicating
- Finding Information
- Making Decisions
- Solving Problems
- Negotiating
- Standing Up for Your Rights
- Topics for Older Persons
- Finding Ways to Pay for Care
- Caring for the Caregiver
- Living Beyond Cancer

Toolboxes are available in the Stephen and Barbara Slaggie Family Cancer Education Center at Mayo Clinic Rochester, Minn., the Patient Health and Education Library at Mayo Clinic Arizona, and on iTumes at www. apple.com/itunes. The toolbox is also available in Spanish and Chinese.

When Your Child Has Cancer:

What Parents Should Know

By Angela Young



If your child is diagnosed with cancer, you may feel overwhelmed and wonder how you are going to manage. The following suggestions may help you find the support and resources you and your family may need during this difficult time.

Become Educated

Your child's oncologist and nursing team will provide information regarding the cancer type and available treatment options or can direct you to appropriate resources. Across all three sites, Mayo Clinic provides access to patient education resources, such as the Stephen and Barbara Slaggie Family Cancer Education Center in Rochester, Minn. In addition, the National Cancer Institute and the American Cancer Society offer information as well as supportive resources that can assist families after a child's cancer diagnosis.

Utilize Available Resources

- **Social workers** have various roles but mainly assist patients with emotional support, provide information about economic resources and make referrals to various community agencies.
- **Child life specialists** educate patients about medical procedures and assist children in developing coping skills. They can also assist siblings in adjusting to the changes.
- **Chaplains** assist patients and families with any spiritual support that may be needed to manage various issues related to the diagnosis.
- **Ronald McDonald House** is an inexpensive home–away-from-home where families can stay to help find support from other families while their children are receiving medical care.
- **Children-related cancer Web sites** offer information and resources specific to children and teens. Examples include: www.candlelighters.org, www.curesearch.org and www.nationalchildrenscancersociety.com.

Find a Local Support Group

In addition to providing hope and inspiration, support groups provide an opportunity for parents to discuss issues related to having a child with cancer. Based in Rochester, Minn., Brighter Tomorrows offers a supportive environment for parents of children diagnosed with cancer. For more information, call Sherrie at (507) 534-3594.

Take Care of Yourself and Your Family

While you may want to devote all or most of your time caring for your child, remember to keep yourself healthy. This may be hard, but to be the best caregiver to your child, you must take care of yourself, too. If you have other children, try to participate in activities with them as well. Also keep in mind that many organizations offer summer camps for children with cancer and their siblings. This allows time for them to be kids and meet others like themselves.

To locate additional resources related to children with cancer, contact an American Cancer Society Navigator in Rochester, Minn., at (507) 266-9288 or Scottsdale, Ariz., at (408) 301-5990; or contact the American Cancer Society at (800) 227-2345 or www.cancer.org.

Angela Young is an American Cancer Society Navigator based at Mayo Clinic Rochester.

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Mayo Clinic
Arizona

Jeri Lensing
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Mayo Clinic
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Rochester

Calendar of Events

January

19 *Multiple Myeloma Sharing Sessions*
10 a.m. – noon
Meets the third Saturday of the month
Gift of Life Transplant House
Rochester, Minn • (507) 259-3979

Cervical Health Awareness Month
National Cervical Cancer Coalition
(800) 685–5531 • www.nccc-online.org

February

15-16 *Multiple Myeloma Sharing Sessions*
10 a.m. - noon
Gift of Life Transplant House
Rochester, Minn. • (507) 259-3979

17 *26.2 with Donna: The National Marathon to Fight Breast Cancer*
Jacksonville Beach, Fla.
(904) 355-PINK
www.breastcancermarathon.com/index.html

March

10-14 *Daffodil Days*
American Cancer Society
(800) 227-2345 • www.cancer.org

15 *Multiple Myeloma Sharing Sessions*
10 a.m. - noon
Gift of Life Transplant House
Rochester, Minn • (507) 259-3979

27-29 *Marching Toward Cancer Prevention*
Professional and public events: clinical symposium, town hall meeting, interactive workshop, community health fair and 5K run/walk
Mayo Clinic Cancer Center
Rochester, Minn. • (507) 266-9087
www.mayoclinic.org/cancer-education-rst/specialevents.html

National Colorectal Cancer Awareness Month
Cancer Research and Prevention Foundation
(800) 227-2732
www.preventcancer.org/colorectal

May

2–4 *Living with a Blood Cancer: A Comprehensive Patient Centered Symposium*
Sponsored by Mayo Clinic
Chicago, Ill.
(507) 288-5620
www.mayo.edu/cme/bloodpatientmeeting/

Event Spotlight

February 15–17, 2008

26.2 with Donna

The National Marathon to Fight Breast Cancer

Jacksonville Beach, Florida

Mayo Clinic and The Donna Hicken Foundation will host the inaugural run of the *26.2 with Donna: The National Marathon to Fight Breast Cancer*, Feb. 15-17, 2008, in Jacksonville Beach, Fla. This event, which will benefit Mayo Clinic and women living with breast cancer, will include a health expo, community celebration event, VIP event, marathon, half marathon and fun run.

As the only marathon in the country dedicated solely to raising money to fight breast cancer, the proceeds will go directly to The Donna Hicken Foundation, an entity that funds the critical needs of underserved women with breast cancer. The foundation has pledged to donate the majority of funds raised to Mayo Clinic's Multidisciplinary Breast Clinic, which specializes in the detection and treatment of breast cancer.

For more information, visit www.breastcancermarathon.com.

together

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The mission of Mayo Clinic Cancer Center is to provide compassionate, state-of-the-art care for the patient with cancer today and continued advancements in the prevention, diagnosis, treatment and cure of cancer in the future. The programs and services of the Cancer Center span the three Mayo Clinic campuses in Arizona, Florida and Minnesota.

together newsletter provides educational information for cancer patients, their family, caregivers and friends. Physicians, staff and cancer patients write the articles. To view the **together** newsletter online, visit www.mayoclinic.org/cancer-education-rst.

To submit story ideas, provide feedback or unsubscribe, call 507-266-9288 or e-mail canceredprogram@mayo.edu.

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