

The Indiana Chapter Newsletter

**LEUKEMIA &
LYMPHOMA
SOCIETY®**
fighting blood cancers

Volume 2;
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*Our mission: Cure leukemia, lymphoma, Hodgkin's disease and myeloma,
and improve the quality of life of patients and their families.*

Finding the Bright Spots

Mike Moulton has always enjoyed taking things apart and putting them back together to understand how they work. He's a mechanic by trade, after all. But, he never thought that he would become so familiar with the intricacies of blood cancer and how it affects the human body. That's just what happened, though, in October 2006. While on a family trip to Disney World, Mike developed a persistent cough. After the trip, he went to an Immediate Care and was treated for a sinus infection. But, worsening symptoms, including a seven pound weight loss within one day, led him to see another physician who prescribed an anti-inflammatory. Still, that didn't help. After he couldn't get out of bed to go for the fasting blood test requested by the doctor, his wife, Carla, took him to the ER. Within an hour after the ER doctor ordered a blood test, the results were returned. It was leukemia, but a specific diagnosis had not been made. Mike recalls, "I knew that it was a blood cancer because my brother-in-law (not related by blood) had been treated for Hodgkin lymphoma." That afternoon Mike was transported to Methodist Hospital by ambulance. His two boys, then ages 4 and 8, spent the night with Mike's mom. A sleepless night ensued. The next day, a bone marrow aspiration was done to confirm the specific diagnosis: acute myeloid leukemia or AML; subtype A6. At that point, Mike admits that he broke down in tears at

the thought of having cancer. A former smoker, he thought he was at risk for lung cancer. Blood cancer had never crossed his mind. An acute diagnosis required immediate action. October 12, 2006 was his first day of a three-week intensive chemotherapy regimen. After twenty-six days in the hospital, however, his journey had really just begun. Mike was released from the hospital for two weeks, although Carla had a sneaking suspicion that he would be readmitted. Sure enough, after having a tooth pulled, he landed back in the hospital for eleven days due to an infection. Eventually after his second consolidation (treatment given to kill as many of the remaining cancer cells as possible) which was five days of chemotherapy, Mike returned home. The holiday season brought reason to celebrate. Mike was in remission. But, it also brought other decisions to consider. Mike met with two hematologists to determine whether an allogeneic transplant (using someone else's stem cells) was the best option. Mike soon learned that without a transplant there was a 95% chance that he would relapse. He remembers telling Carla, "If I die, you're too young to go through life without finding another spouse. But, I'm going to fight this." An allogeneic transplant, while risky, seemed like the best option. Mike was, in some ways, lucky. He had four sisters who could be tested as potential donors. On average, an individual has a one in four chance of having the same HLA (human leukocyte

antigen— proteins on the surface of most tissue cells that give an individual his unique tissue type) as his sibling. Mike was unusual in that two of his four sisters were matches. Maura, who does not have children, was chosen to be the donor since she had not been exposed to different DNA during a pregnancy. Mike's transplant took place on March 15, 2007, and he was inpatient at IU Hospital for about a month. After being discharged, an infection landed him back in the hospital for eleven days. In addition, Mike developed a condition called Graft Versus Host Disease (GVHD). This occurs when the transplanted donor immune cells attack the patient's body, resulting in various side effects. Mike developed chronic GVHD and began referring to himself as Barney because the skin on his face took on a purple-like appearance similar to the cartoon character. The steroid, Prednisone, was prescribed and although Mike still deals with GVHD, it has lessened in its severity.

Today, Mike happily reports that he is six years post-

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Mike Moulton, AML survivor, at the Indianapolis Light The Night Walk.

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Spotlight on Light The Night®

Mike's story (see *Finding the Bright Spots* on page 1) is a shining example of why the Light The Night Walk changes the lives of the patients The Leukemia & Lymphoma Society (LLS) serves. Light The Night (LTN) is one of LLS's priority fundraising campaigns. With annual walks held in September and October in Crown Point, Lafayette, Fort Wayne, Kendallville and Indianapolis, it is one of the most effective ways a family, group of friends, company or organization can make an impact on the LLS mission. At LTN, patients, survivors, caregivers and supporters walk along a two-mile route carrying illuminated balloons –white for patients and survivors, red for supporters and gold for teams walking in memory of a loved one. The family-friendly events provide a host of activities, entertainment and festivities for all ages. It is an evening where teams commemorate and celebrate their team's honored hero or heroes. In addition to families and friends who fundraise, an important element to the walk's success is corporate

support. Many companies provide LLS with sponsorship funds, recruit teams from their employee base and match gifts their employees make. This year, we are especially proud to welcome Marsh Supermarkets as our top corporate supporter. In addition, Marsh will sell LTN Paper Balloons at the checkout aisles during the month of October. With Marsh's support and the help of families, friends, patients, caregivers and other companies, we hope to raise nearly \$850,000 across the state this year. You might ask, "Why is there such a high goal?" or "Why does LLS raise money?" Great questions! We engage the community to work hard so we can change the lives of the patients we serve now and of those diagnosed in the future. Funds raised through LTN participation support the LLS mission in various ways: To fund research—LLS has two research programs to help support its mission. The first is the Research Grant Program, which is comprised of three separate grant mechanisms. The second research program is the Therapy Acceleration Program (TAP). TAP bridges the gap between discovery and human application by putting treatments and tests into preclinical trials. This is accomplished by working with academic investigators, medical centers and companies. LTN also impacts patients and their families by helping to

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2012 Light the Night Walk Dates

September 18 | NE Indiana, East Noble High School
 September 20 | Greater Lafayette Area, Riehle Plaza
 September 23 | NW Indiana, Lake County Fair Grounds
 September 23 | Fort Wayne, Freimann Square
 October 13 | Indianapolis, Victory Field™



Meet Your Indianapolis Walk Honored Hero: Joe Kieffer

Providing inspiration to those who fundraise for Light The Night.

Joe was diagnosed with Acute Lymphocytic Leukemia (ALL) in July 2011 and is currently in remission. As a senior at Roncalli High School his favorite activities are wrestling, golf and hanging out with friends. Joe's role models are his mom, Jenny, and dad, Kevin. His favorite movie is *Remember The Titans* and his favorite book is *Four Days of Glory*. His goal is to raise money and promote fundraisers so that we can better our chances of finding a cure.

Finding the Bright Spots continued from page 1...

transplant and his doctor used the word "cured" at his last appointment. What is amazing is that throughout all of the bumps in the road, Mike has found the bright spots and reason to give back. He views the past six years as an opportunity he otherwise wouldn't have had to spend time with his two boys, now ages 10 and 13. He also recalls hearing an ad on the radio for Light The Night when he was in the hospital in 2006. He promised that he would participate in the Walk the next year if he made it through treatment. Following through on that

promise, he began participating in Light The Night in 2007. Still very weak that first year, he refused to stop walking. He also believes it is important to inspire other individuals who are just beginning this journey. So, he became a First Connection Volunteer to offer support to others currently in treatment for AML. In addition, he has aspirations to return to work within the next year or two. As a true fighter, his mindset is, "Even when I get down, I have to think at least I'm still alive."

It's not too late to make an impact on Light The Night® this year!

Volunteers are needed for the Indianapolis Light The Night Walk on October 13, 2012 at Victory Field. Shifts are from 4:30 to 7 p.m. and include registering walkers, greeting and directing walkers, filling balloons and passing out advocacy information. Volunteers are needed from 4:30 to 9:00 pm to count and verify donations. All ages are welcome, and we invite you to join us for the program and Walk once your shift is over! For more information or to sign up, contact Laura O'Brien at (317) 860-3849 or laura.obrien@lls.org.

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support a variety of programs to help ensure that the quality of life of patients and their families is improved. All of LLS's programs and services are offered free of charge. These programs and services include the Patti Robinson Kaufmann First Connection Program, Family Support Groups, Education Programs, Patient Financial Aid, Co-Pay Assistance Program and the Information Resource Center (IRC). Walk with us and know that you are impacting the research being done to find a cure and the programs LLS provides for patients and families.



Right: Walkers starting the Light The Night Walk at Victory Field™ in Indianapolis.



PENNIES FOR PATIENTS

Pennies for Patients is gearing up to recruit **600 Indiana schools** to participate in our program during February and March 2013! Interested in getting your local school involved or volunteering with Pennies for Patients? Contact Elissa Evernham at elissa.evernham@lls.org or (317) 860-3845 to learn how.



TEAM IN TRAINING

Are you looking for a way to support someone who has been affected by blood cancer? Join Team In Training! Help us build the largest Walt Disney World Marathon team the Indiana Chapter has ever had, tackle Eagle Creek Park or be part of the inaugural Hero-thon Powered by LLS in San Antonio. With lower fundraising goals and shorter distance options, there is an event for everyone this season.

Visit www.teamintraining.org/in for all the details!

New Drug Shows Promise for Treatment of AML

The Leukemia & Lymphoma Society (LLS) and Celator Pharmaceuticals, Inc. have agreed to an expansion of their partnership to support clinical development of CPX-351, Celator's therapy for adults with acute myeloid leukemia (AML). With this agreement, LLS will provide \$5 million in funding, through its *Therapy Acceleration Program (TAP)*, for the pivotal, Phase 3, multicenter trial of CPX-351 versus conventional cytarabine plus daunorubicin in elderly patients with untreated secondary AML. Enrollment in the study is expected to begin later this year. Should the results confirm that CPX-351 improves overall survival, the study will be used to support a New Drug Application (NDA) for CPX-351 in this indication with the U.S. Food and Drug Administration (FDA). CPX-351 is two chemotherapy

drugs packaged in a special way to ensure a specific ratio gets directly to the leukemia cells. The cells are encased in fat droplets, nestled together like microscopic Russian dolls. "This is the first time that LLS has provided follow-on funding to a development partner," said Louis J. DeGennaro, Ph.D., LLS's chief mission officer. As part of a 2009 partnership, LLS provided \$4.1 million to help fund Celator's Phase 2B trial of CPX-351 for patients with relapsed AML. DeGennaro went on to say, "The very promising results of our initial collaboration, as well as Celator's demonstrated ability to pursue its research agenda effectively while working with the FDA to identify an efficient regulatory pathway, give us the confidence to provide an additional \$5 million to make CPX-351 available to patients with AML as soon as possible."

**Patient financial aid (\$100) is available.
To receive a new application, contact Claire Kammen.
(800) 846-7764 or claire.kammen@lls.org.**



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Registration for all events is required.

To register, contact: (800) 846-7764.

September 19 | Celebration of Life | 6:00 p.m. | Indianapolis, IN | Join The Leukemia & Lymphoma Society and St. Francis Hospital for an evening catered to blood cancer survivors who are one-year post diagnosis. Come for dinner and help us decide the format and content for future gatherings. Caregivers are welcome. Register by: September 17.

September 26 | Staying Connected: Facilitating the Learning Experience During and After Cancer Treatment | 5:15 pm | Ft. Wayne, IN | School, college personnel and parents will learn about the effects of childhood, adolescent and young adult cancer treatment. In addition, participants will learn how to improve a child's transition back to school once treatment is over. Register by: September 24.

September 27 | The Affordable Care Act: How will you be Affected? | 6:00 p.m. | Indianapolis, IN | If you've asked yourself this question, then this is the program for you! Receive information about our health insurance framework: Medicare, Medicaid, COBRA, the State High Risk Insurance Pool and HIPAA, as well as upcoming changes under the Affordable Care Act. Register by: September 24.

October 4 | Staying Connected: Facilitating the Learning Experience During and After Cancer Treatment | 5:15 pm | Indianapolis, IN | School, college personnel and parents will learn about the effects of childhood, adolescent and young adult cancer treatment. In addition, they will learn how to improve a child's transition back to school once treatment is over. Register by: October 1.

October 17 | Flossing and Flexing | 6:00 p.m. | Indianapolis, IN | Physical health and oral health are very different, yet both play a role in the road to survivorship. Join this husband and wife team to learn simple exercises that will maintain and restore strength and impact overall well-being. Develop an understanding of good oral hygiene during and after chemotherapy, learn about cosmetic treatments to enhance your smile and general recommendations for taking care of your oral health. Register by: October 15.

October 25 | Leukemia x 4 = Education + Dinner | 6:00 p.m. | Ft. Wayne, IN | It's here: A gathering with Dr. Dennis O'Brien to learn about the four main types of leukemia (ALL, AML, CLL, CML) — In addition to updates about research and promising treatments in the pipeline, bring your questions and receive answers. Register by: October 22.