The following abstracts related to the SPORE were selected for presentation at this year’s American Society of Hematology meeting, held December 5-8, 2015. The following abstracts related to the SPORE were selected for presentation at this year’s American Society of Hematology meeting, held December 5-8, 2015.
Since I was four years old, I have always loved to swim. I have been a U.S. and Iowa Masters swimmer for decades (breaking nearly 30 records over the years), and 2012 was an especially fun year in the pool for me. So when I started having some back pain in December of that year, I just assumed it was a muscle strain. Then on a trip to LA in January, when my back pain became suddenly intense, with corresponding leg pain — requiring a wheelchair to get back through the airports, I knew something was seriously wrong. I had an MRI the day after I got home and was told I had a spine tumor that was crushing one of the nerves that helped control my ability to stand and walk.

My initial treatment included a six-hour spine surgery which removed most of the tumor, but the report came back that it was an aggressive Lymphoma. My treatment then included six rounds of outpatient RCHOP, two 5-day hospital stays for high-dose methotrexate, and 20 sessions of radiation. I was in the wheelchair for many months and my white blood counts were so low that the only place I went for seven months was to the hospital. I found that during my illness, the best way to cope with everything was to persistently focus on taking things day by day, sometimes hour by hour. And I always rewarded myself every night (without fail) with a bowl of ice cream (I’m partial to chocolate chip).

So, given that in the spring of 2015 I was 18 months in remission (although still suffering from some ongoing side effects), I wanted to do something special to celebrate National Cancer Survivors Day. And since I was now able to get back in the pool 2-3 times a week, I entered three swimming events at the Quad Cities Senior Games held on June 6 at Augustana College in Illinois (about an hour from our Iowa City home — which was the furthest I had travelled since early 2013).

As I was warming up before my first swimming event, so much of the past 2½ years was running through my mind. It was nearly overwhelming to think of how sick I had been and all of the doctors, nurses, and technicians who played such a role in my treatment and recovery. So I focused solely on the opportunity I was given to again do what I love and was thinking that this first meet back was a way to honor my incredibly skilled and compassionate team at the Holden Comprehensive Cancer Center here at the University of Iowa who not only saved my life, but also helped me to swim again. Long story short: 3 gold medals and 3 Quad Cities Senior Games records (100, 200, 500 yard freestyle events) — I could not be more grateful.
Meet Our Investigators

GAIL BISHOP, PHD
Principal Investigator: Developmental Therapeutics Program
University of North Carolina at Chapel Hill

Gail grew up in Milwaukee, WI, earned her B.A. in Biology at St. Olaf College in Northfield, MN, an M.S. in Oncology at The University of Wisconsin-Madison, and her Ph.D. in Cellular & Molecular Biology at The University of Michigan. She performed postdoctoral research at The Mayo Clinic where she serves as Director of the SPORE Biospecimens Core in 2013. Outside of work he enjoys music, hiking, baseball, and spending time with his two sons, Eric and Ian. Outside of work, she enjoys

ANDREW FELDMAN, MD
Director: Biospecimens Core

Our project is focused on a three-step approach to capturing the ability of the immune system to reject lymphoma tumors. In the first step, we are detecting the genetic death of lymphoma cells in a way that allows the immune system to recognize and reject the tumor. This is called immunogenic tumor cell death and is important for the development of vaccines. The second step is to immunize against these tumors, which is important for the development of vaccines. The third step is to stimulate the immune response to the vaccines, which is important for the development of vaccines. This project is investigating a signaling pathway that cancer cells use to grow and spread, which is referred to as the JAKSTAT pathway. Our group has shown that this pathway is activated in certain types of lymphoma, which are the most common types of B-cell lymphoma. We have also shown that the activation of immunogenic tumor cell death is important for the treatment of lymphoma. In the past several years, our group has shown that the JAKSTAT pathway is activated in certain types of lymphoma, which are the most common types of B-cell lymphoma. We have also shown that the activation of immunogenic tumor cell death is important for the treatment of lymphoma. In the past several years, our group has shown that the JAKSTAT pathway is activated in certain types of lymphoma, which are the most common types of B-cell lymphoma. We have also shown that the activation of immunogenic tumor cell death is important for the treatment of lymphoma. In the past several years, our group has shown that the JAKSTAT pathway is activated in certain types of lymphoma, which are the most common types of B-cell lymphoma. We have also shown that the activation of immunogenic tumor cell death is important for the treatment of lymphoma.
CORES

Biospecimen Core and the number of samples currently managed by the Biospecimen Core can be found in the tables below:

The Biospecimen Core is responsible for the collection, processing and storage of all blood samples that are collected from participants. In addition, tumor samples are processed and stored. Another function of the Biospecimen Core is to build tissue microarrays (TMAs). A TMA is a paraffin (wax) block where cores of tumor blocks are placed together on one block, so multiple samples can be studied at one time. The Biospecimen Core also devotes time to developing new lab methods. The members of the Biospecimen Core and the number of samples currently managed by the Biospecimen Core can be found in the tables below:

<table>
<thead>
<tr>
<th>Name</th>
<th>Title</th>
<th>Role</th>
<th>Role</th>
</tr>
</thead>
<tbody>
<tr>
<td>Andrew Feldman, MD</td>
<td>Hematopathologist</td>
<td>Core director</td>
<td></td>
</tr>
<tr>
<td>Sergei Syrbiu, MD</td>
<td>Hematopathologist</td>
<td>Core co-director</td>
<td></td>
</tr>
<tr>
<td>Anne Novak, PhD</td>
<td>Assistant Professor of Medicine</td>
<td>Co-Investigator</td>
<td></td>
</tr>
<tr>
<td>Tammy Rattle, Lab Technician</td>
<td>Processes all lymphoma samples</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lindsay</td>
<td>Clinical Research Coordinator</td>
<td>Manages samples used in projects</td>
<td></td>
</tr>
<tr>
<td>Juliane Lunde</td>
<td>Program Manager</td>
<td>Oversees project movement through core</td>
<td></td>
</tr>
</tbody>
</table>

Biospecimens Samples managed by the Core:

<table>
<thead>
<tr>
<th>Subtype</th>
<th>Peripheral Blood DNA</th>
<th>DNA from tumor</th>
<th>Serum</th>
<th>Plasma</th>
<th>Cells from tumors</th>
</tr>
</thead>
<tbody>
<tr>
<td>Composite Histology</td>
<td>281</td>
<td>39</td>
<td>207</td>
<td>194</td>
<td>32</td>
</tr>
<tr>
<td>Diffuse large B-Cell lymphoma (DLBCL)</td>
<td>1299</td>
<td>209</td>
<td>1008</td>
<td>934</td>
<td>46</td>
</tr>
<tr>
<td>Follicular lymphoma</td>
<td>1079</td>
<td>32</td>
<td>854</td>
<td>848</td>
<td>92</td>
</tr>
<tr>
<td>T-cell lymphoma</td>
<td>397</td>
<td>0</td>
<td>299</td>
<td>280</td>
<td>25</td>
</tr>
<tr>
<td>Hodgkin lymphoma</td>
<td>524</td>
<td>0</td>
<td>396</td>
<td>345</td>
<td>31</td>
</tr>
<tr>
<td>MCL</td>
<td>315</td>
<td>0</td>
<td>270</td>
<td>261</td>
<td>34</td>
</tr>
<tr>
<td>MZL</td>
<td>493</td>
<td>14</td>
<td>371</td>
<td>367</td>
<td>69</td>
</tr>
<tr>
<td>Other B-cell lymphomas</td>
<td>593</td>
<td>2</td>
<td>459</td>
<td>448</td>
<td>34</td>
</tr>
<tr>
<td>Chronic lymphocytic leukemia (CLL)</td>
<td>1311</td>
<td>10</td>
<td>153</td>
<td>119</td>
<td>44</td>
</tr>
<tr>
<td>Other Non-Hodgkin lymphoma</td>
<td>186</td>
<td>1</td>
<td>145</td>
<td>137</td>
<td>7</td>
</tr>
</tbody>
</table>

Meet Your Patient Advocates!

Ben Haines
In March of 1997, when my wife and I were 31, she was diagnosed with ‘incurable’ stage IVB lymphoma. Devastating news, but thanks to the lymphoma doctors in this very Lymphoma SPORE she is alive and well today. That is all the motivation I need to back with advocacy. My favorite part of being an advocate is working alongside the doctors; before it always seemed like a ‘black box’ but now I know they are working tirelessly with the NCI, each other, and other hematologists around the world, collaborating, saving lives, and working for better treatments in the future. We reside in Minneapolis, Minnesota, and adopted a girl from Ukraine, now 12, and have two dogs. Lymphoma is a word, not a sentence.

Bob Paschke
I am a 5 time survivor of Hodgkin’s Lymphoma. After my Hodgkin’s returned shortly after my bone marrow transplant, I was given a pretty grim prognosis. However, thanks to new breakthrough drugs on clinical trials, the support of others, and God’s Amazing Grace, I have been having a great life with lasting remissions with minimal side-effects. I have been involved in the Cancer Community since my diagnosis and have been very involved in the Lymphoma Research Foundation. I got involved in SPORE just recently in 2015. I think it is very important to support the core research that will inspire the next generation of breakthrough treatments. I have found that the best way to fight this terrible disease is to get involved and help others.

Personally, I love spending time with my three kids and wife. We enjoy traveling and going to lots of soccer and football games.

Lorraine Dorfman
I have been the University of Iowa patient advocate since the inception of the SPORE grant, which began shortly after my husband Donald died of the disease after a 14 year battle. Although I knew that I could no longer help Don, I hoped I could help others with lymphoma. I have enjoyed my association with the SPORE for many reasons: the feeling that I am part of the lymphoma effort; the rewards of learning about the many accomplishments of the researchers and clinicians participating in the project; and helping the SPORE in any way that I can. If you or your family members would like to contact me personally, please feel free to do so at lorraine-dorfman@uiowa.edu. In terms of my personal background, I am professor emerita in the School of Social Work and interdisciplinary Aging Studies Program at the University of Iowa, where for many years I specialized in teaching and research in the field of aging. I have two grown children and two grandchildren, who are a great joy to me. I enjoy travel, reading, gardening, community activities, and am a yoga enthusiast.

Research Support
As patient advocates for the UI/UC Lymphoma SPORE, we have seen personally how the SPORE team is contributing to progress against lymphoma. We, and the other members of the UI/UC Lymphoma SPORE team, are grateful to the National Cancer Institute for ongoing federal support of our collaborative research program. However, cancer research funding by the government is under considerable budgetary stress and is not adequate to support all of the lymphoma research being conducted and planned by the SPORE team. Without private support, some promising lymphoma research projects cannot be pursued. To learn more about how private support helps strengthen the research being conducted through the SPORE, please go to www.uifoundation.org or contact Sarah Russell at the University of Iowa Foundation at sarah.russell@uiowa.edu.

Thank you—Ben Haines, Lorraine Dorfman, and Bob Paschke: Patient Advocates University of Iowa/Mayo Clinic SPORE
New Funding From the National Cancer Institute to Study Lymphoma Survivorship

Building from the great success of the Molecular Epidemiology Resource (MER) of the SPORE, we decided to apply for a grant from the National Cancer Institute to expand the MER cohort to more regions in the United States. In May, we heard that we will be funded to expand to six new centers over the next 5 years, which will increase the size of the cohort from 5,000 to over 12,000 lymphoma patients. The new cohort will be called “LEO” which stands for Lymphoma Epidemiology of Outcomes. The goal of the cohort study will be to identify factors that improve lymphoma survivors’ length of life and quality-of-life.

Besides Mayo Clinic and the University of Iowa, new institutions include Emory University/Grady Health System in Atlanta, Georgia; MD Anderson Cancer Center in Houston, Texas; Cornell University in New York, New York; the University of Miami Health System/Jackson Memorial Hospital in Miami, Florida; University of Rochester Medical Center in Rochester, New York; and Washington University in St Louis, Missouri. Drs. James Cerhan (Mayo) and Chris Flowers (Emory) are Co-Principal Investigators and Drs. Brian Link (Iowa) and Thomas Habermann (Mayo) are co-Leaders of the Clinical Core. Dr. Andrew Feldman (Mayo) will lead the Pathology Core, and Dr. Susan Slager (Mayo) will lead the Biostatistics and Bioinformatics Core. Drs. George Werner and Thomas Witzig will serve on the Steering Committee.

We held our “kick-off” meeting in Atlanta in July – over 50 people who work on the study attended, including study coordinators, physicians, pathologists, epidemiologists, and biostatisticians. We also picked a logo for LEO which you see in this newsletter!

Biostatistics and Bioinformatics Core

The Biostatistics and Bioinformatics Core is directed by Drs. Susan Smith, Terry Braun, and Susan Slager. The Core provides statistical and informatics support for the University of Iowa/Mayo Clinic SPORE projects, developmental projects, and the other cores. It also actively collaborates with and supports the Molecular Epidemiologic Resource. Core members develop study design and data analysis plans for projects initiated in the SPORE, analyze study data, perform data management for each of the clinical trials, monitor adverse events in collaboration with the Clinical Research Core, and prepare data summaries for publication. Bioinformatics expertise is provided and includes custom development of algorithms, software, machine learning, databases, interfaces, and web-based programs. Recent activities include: i) the development and execution of a next-generation sequencing pipeline to analyze DNA samples from cancer patients, ii) the development of web-based forms for the entry of clinical and diagnostic data to support clinical and molecular studies, and iii) integrating PET and CT imaging data with clinical and treatment data to help predict clinical outcomes.

Clinical Research Core

The Clinical Research Core, co-chaired by Drs. Thomas Habermann and Brian Link, is important because it has the dual function of partnering with the Molecular Epidemiology Research (MER) project which follows patients for outcomes and the Clinical Research Core coordinates the clinical trial programs for the SPORE. There are now 6,952 patients enrolled and in follow-up. Since the last grant cycle, new collaborations in the United States with institutions such as the University of Arizona, Roswell Park and other institutions have been established to complement previous collaborations such as the Dana Farber Cancer Institute and The Broad Institute. New international collaborations have been established with institutions in France, Sweden, and Italy. In addition, the MER has contributed to genome wide association studies through other study groups such as InterLymph which include institutions world-wide. The breadth of these collaborations in the field is unprecedented and moves observations forward at a very rapid pace.

A unique aspect of this program is that patients are followed after their initial clinical evaluation and consent to provide a peripheral blood sample, utilize tissue for research and responses to multiple questions in a booklet are used to study multiple patient background issues that often include the use of samples from the peripheral blood. Multiple genetic studies have helped advance the science of lymphoma, by contributing to large genome wide association studies (GWAS) in Hodgkin lymphoma, diffuse large B-cell lymphoma (DLBCL), chronic lymphocytic leukemia, and other lymphoproliferative disorders.

Variations in genes in several pathways in lymphoma have been reported and are under further evaluation.

The Clinical Research Core’s extensive patient data base has allowed for new and unique clinical observations and a number of studies not otherwise possible, which directly helps patients. Over 87 papers have been published over the last four years. For example, a personalized risk prediction model for DLBCL patients alive and disease free after 24 months; the QxCalculate clinical calculator phone app which is available free (www.qxmd.com) which predicts the chances of being alive and event free at the time of the initial presentation. The many investigators in the SPORE grant are most grateful to our patients for participating.
Many participants have several questions about this project throughout the consenting process and during the follow-up interviews. Below, you will find some of the most frequently asked questions. Answers have been provided by the research team.

**If I get my care done at another hospital can I still participate?**

Yes! There are many participants who are a part of the registry that do not return consistently to the University of Iowa or Mayo Clinic for their care. We have practices in place to assure your continued participation in the study. One example of how distant participation occurs is our follow-up questionnaire. Completion of follow-up forms not only strengthens our data, it also allows us to keep in contact with you if you receive care at an outside hospital or clinic. The information collected in the follow-up questionnaires is critical to the research we are conducting.

**Can I receive the mailed follow-up questionnaires electronically?**

Unfortunately, at this time we cannot send the follow-up questionnaires electronically. We are beginning the process to discover and build electronic forms that can be used to send follow-ups via email or through medical record communication (i.e. MyChart or Patient Portal). It is our hope that in the near future we can offer enrolled participants the ability to receive the follow-up questionnaires electronically. Follow-up questionnaires are sent twice a year to participants during the first three years of enrollment, then annually thereafter.

**What is being done with my blood that is collected and stored?**

The samples collected are being used to study new tumor/disease markers that might shed light on why one gets lymphoma, why someone responds or does not respond to a specific treatment and predictions on how one will react to their disease in general. As cancer research continues, new markers are frequently being discovered. By keeping a portion of your blood in storage, it allows us to study new markers as they are discovered. We update the status of all participants’ disease, including how the lymphoma responds to specific treatments, in the clinical database so we can answer important questions related to the value of a new marker. The research team greatly appreciates your willingness to provide the samples.

**I recently had blood drawn at another facility; can I have them send you some of that blood for your project?**

We cannot use any samples that are drawn as routine care from other hospitals or clinics. The blood and tissue that is collected for this study needs to be whole and pure and assure that future testing will be done accurately. We also need the blood to be collected in specific research tubes. It is important in research to use consistent standard procedures throughout the span of the study. We try to be flexible with blood collections and coordinate the draw with your normal clinical appointments at the University of Iowa or Mayo Clinic in Rochester whenever possible.

**Do I need to come back to Mayo Clinic or The University of Iowa for research appointments?**

No. This is an observational study, which means we will follow you through questionnaires, phone calls and at times, quality of life once you are being seen for routine care.

**Who is the research team?**

The lymphoma SPORE/MER research team consists of investigators, study coordinators, lab technicians, pathologists, statisticians, clinicians, patient advocates and students who all work together to collect, store, and analyze data and specimens. The University of Iowa and Mayo Clinic research teams work closely together to assure the continued success of the MER.

**Thank you for your participation**

We want to express our sincere appreciation to you for participating in this study, and for being willing to share your information and samples of your blood. It is only through your generosity that we are able to study new aspects of these diseases and publish our results, such as in the examples below. We realize that at the time we approach you in the clinic/hospital to participate in the study, you may have just learned about your diagnosis, and you may have many questions. Please feel free to contact us at any time and we would be happy to answer any question you may have. University of Iowa: 800-237-1225; Mayo Clinic: 800-610-7093.

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**A few recent MER publications:**


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**SPORE Registry Update & FAQ**

**MER Publication Spotlight**

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**MER Accrual by Month**

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**Cumulative Patient Enrollment**