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## CLL Expert Describes Exciting Advances

John C. Byrd, MD

**“It’s important for patients to understand how advances in chronic lymphocytic leukemia (CLL) are expanding our options for therapy. This field is moving forward very quickly,”** explains Dr. John Byrd, CLL expert from The Ohio State University Wexner Medical Center. Dr. Byrd will discuss these advances when he presents The Leukemia & Lymphoma Society’s (LLS) upcoming live telephone/web education program.

### GENETICS AND TARGETED THERAPIES

**“CLL is not a common disease. When you break CLL down into smaller genetic groups, the treatment becomes very individualized,”** says Dr. Byrd. He explains that the future is today in terms of personalizing treatment for CLL patients based on the genetics of their disease. “There are a variety of genetic markers that we are learning are very important to consider in deciding when and how to treat patients who have CLL. At the time of diagnosis, it’s recommended that patients have a FISH (fluorescence *in situ* hybridization) test. FISH testing can identify markers, including 17p and 11q deletion, which help physicians determine the most appropriate treatment approach.” Dr. Byrd explains that other genetic markers are being identified which may further direct therapy in the future. As researchers learn more about the genetics of CLL, they are able to develop therapies targeting those mechanisms that allow CLL cells to grow. Dr. Byrd shares his enthusiasm for new targeted therapies currently in

clinical trials for CLL, including ibrutinib and GS-1101, both of which are in the class of drugs known as the B-cell receptor signaling inhibitors. “In clinical trials, these targeted therapies are showing great promise, even in patients with high-risk genetic markers. They have the potential to transform the landscape of CLL therapy and possibly replace chemotherapy as our first line of treatment.”

### A TEAM APPROACH TO TREATMENT

Because the field is advancing at such a rapid rate, Dr. Byrd stresses the importance of patients having a CLL expert involved in their care. “At CLL centers of excellence, we often see patients soon after their diagnosis. We review their tests, make them feel more comfortable with their disease, and usually affirm the good care they are receiving at the local level. If a clinical trial is available, we can offer and coordinate that. Patients might then follow up with a CLL specialist yearly while seeing their local doctor more frequently. This allows patients to have the best team involved in their care, without having to travel hours to have care that can be done closer to home. I personally think if I had CLL that is the model I would want to take.”

He encourages patients to reach out to LLS for information about how to find a CLL specialist and for up-to-date CLL information. You will also have the opportunity to learn more about CLL from Dr. Byrd on **May 1, 2013** when he presents the LLS telephone/web education program, **Update on CLL**.

**REGISTER TODAY!**

**FREE TELEPHONE/WEB EDUCATION PROGRAM**

UPDATE on **CLL**

WEDNESDAY, MAY 1, 2013  
1:00 PM – 2:00 PM ET

**Three ways to register:**

Visit [www.LLS.org/programs](http://www.LLS.org/programs)

Call toll-free  
(866) 992-9940 (x315)

Scan QR code

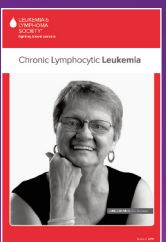


Ask Dr. Byrd a question during the Q&A session

### CLL Word to Know – Fluorescence *In Situ* Hybridization (FISH)

A technique for studying chromosomes in tissue using DNA probes tagged with fluorescent molecules that emit light of different wavelengths (and different colors). The probes match to the chromosomes...

Read the full definition of **Fluorescence *In Situ* Hybridization (FISH)** and other important CLL *words to know* in the glossary of medical terms on pages 29-40 of the LLS *Chronic Lymphocytic Leukemia* booklet. ([www.LLS.org/resourcecenter](http://www.LLS.org/resourcecenter))





## Did you know?

LLS has chapters across the United States and Canada.

### Reach out to your LLS chapter to get involved!

Like Bob, you can get involved with an LLS chapter in your community. Visit:

[www.LLS.org/chapterfind](http://www.LLS.org/chapterfind)

To learn more about LLS events like Team In Training® or Man & Woman of the Year, visit:

[www.LLS.org/waystohelp](http://www.LLS.org/waystohelp)

## CLL RESOURCES ARE JUST A CALL OR CLICK AWAY!

- Support from Patient Services Managers at LLS chapters  
[www.LLS.org/chapterfind](http://www.LLS.org/chapterfind)
- Booklets, fact sheets, and other print materials, including *Chronic Lymphocytic Leukemia* and *The CLL Guide: Information for Patients and Caregivers*  
[www.LLS.org/resourcecenter](http://www.LLS.org/resourcecenter)
- Live and archived telephone/web education programs  
[www.LLS.org/pastprograms](http://www.LLS.org/pastprograms)
- One-on-one peer support through the *Patti Robinson Kaufmann First Connection Program*  
[www.LLS.org/firstconnection](http://www.LLS.org/firstconnection)
- Support Groups  
[www.LLS.org/supportgroups](http://www.LLS.org/supportgroups)
- Financial assistance  
[www.LLS.org/finances](http://www.LLS.org/finances)

Call an LLS Information Specialist toll-free at (800) 955-4572 or email [infocenter@LLS.org](mailto:infocenter@LLS.org) for more information.

## New Web Videos from LLS!

- *Cancer and Your Finances*
- *Advances in Blood Cancers: Update on Treatment for NHL and CLL*

Participate today at:

[www.LLS.org/webcasts](http://www.LLS.org/webcasts)



# Making a Difference Today



Bob and his family at a Team In Training® event

When Bob McIntyre was told he had CLL, eight years ago, at the age of 45, he says it was like getting hit by a bus. His primary physician had referred him to an oncologist after routine tests showed a high white blood cell count. He explains, “I had gone to the appointment by myself. When they told me I had leukemia, my first thought was, ‘how am I going to tell my wife and three daughters?’ That was the worst part of it.”

The oncologist’s office suggested he call The Leukemia & Lymphoma Society (LLS). He was connected with Karen DeMairo, the Senior Patient Services Manager at his LLS Chapter on Long Island. Karen explained more about CLL and asked him if he would like to talk to someone with the same diagnosis. Bob says, “At the time, I felt like I was the only one on the planet with this. Karen put me in touch with someone my age who also had young kids. All I wanted to hear was that he had this same crazy thing and he was going ahead with his life. Hearing that he was really helped me to move forward.” His experience motivated him to become a *Patti Robinson Kaufmann First Connection Program* volunteer. “Through the program, I’ve been able to make some phone calls to other people who’ve been hit by this bus, and I think it’s definitely made a difference for them as well.”

## “Do something you can feel good about.”

Bob has not required drug therapy for his CLL. He is followed by a CLL specialist and receives regular check-ups, including blood tests. He stays current on available treatments by attending education programs at his LLS chapter. “I don’t know what my future will hold, but I have faith that we are getting close to finding a cure for CLL. In the meantime, I don’t want to be sitting on the sidelines not making a contribution. The only way I can feel like I’m fighting is to try to keep myself healthy and try to raise some money to help find that cure.” He does both of those things through his involvement with Team In Training®, the LLS fundraising program in which individuals take part in running, cycling or hiking events to raise money for blood cancer research and patient services. Bob explains, “When I went to my first Team In Training meeting, I hadn’t exercised in years. I was walking around with all of these athletes wondering what I got myself into. When I went home and told my wife I joined the LLS cycling team, she said ‘you don’t even have a bike!’ Team In Training gave me a training schedule and I followed it. I started to exercise and it felt good. I eventually I bought a used bike and that was the start of my Team In Training career.” Since then, Bob has run three marathons, a half marathon, completed seven 100-mile bike rides, and eight triathlons, raising over \$100,000 for LLS. “I actually think I’m in better health now than before I was diagnosed.” Bob participated in the 2013 Disney Goofy’s Race and a Half Challenge (a 39.3 mile race event) and was also the runner up last year for LLS Man of the Year at his chapter, raising over \$30,000 through local events including 5K runs held in memory of a family friend. Karen DeMairo explains, “Many of our volunteers, like Bob, start out as patients who reach out to us for help. When they see how important our work is, they want to give back. Volunteers like Bob help bridge the gap between what we do in patient services—providing patients with information, resources and support, and how we get there—through fundraising. We couldn’t achieve our mission without their help.”

Bob says it is the people he has met who make him so committed to LLS. “Once you start getting involved, you have all these people supporting you. They are my heroes. It may be hard to understand, but because of LLS and Team In Training, my life is better now than it was before I was diagnosed.” His advice to others is simple: “Call LLS for support, and when you’re ready, get involved. Do something you can feel good about.”