

## **Conclusion**

### **Narrator**

The purpose of this program has been to help you and your family and friends better understand and live with CLL. CLL is a complex disease. When first diagnosed, there is so much to learn and adjust to that it often seems overwhelming. Eventually, you and your family learn the language of leukemia and you become an expert about your treatment and care. The resource booklet that accompanies this *Toolbox* program contains many tips and resources to help you manage your life after getting a diagnosis of CLL. You will find definitions for the terms used in this program, and a list of all of the resources mentioned including phone numbers and internet addresses. There are also some suggested references and articles or books that you might find useful.

In order to live well with CLL, you must become your own best advocate. You know yourself and your body better than anyone else. Ask for what you need, and let your health care team know if you need more information or support, or if you think you are developing a new problem. As time goes by, you will learn to manage and live fully with this chronic illness.

In this program, we've met cancer survivors, their loved ones and caregivers, and health care professionals. Let's review some of the important points we've learned from them.

- Everyone diagnosed with cancer is a survivor – from the moment of diagnosis onward.
- CLL can be complex; so can its treatment.
- Most people with this illness need some form of treatment throughout their lives, so it's important for you to know about common symptoms and side effects of the disease and treatment and how to control and manage them.

- You can't alter the fact that you have been diagnosed with CLL, but you can learn to adapt to it and to manage the necessary life changes required to live as fully as possible after your diagnosis.
- Although CLL is not as common as some other cancers, you are not alone. There are thousands of others, who like you, are figuring out how to live and cope with CLL and its symptoms, side effects, and uncertainties.
- There are many clinical trials in progress now, a good sign that we will continue to see new forms of treatment for CLL. We have reason to be very hopeful.
- There is good information about clinical trials for CLL on web sites offered by the National Cancer Institute and The Leukemia and Lymphoma Society.
- The battle of CLL is hard to fight alone; support helps.
- Know that there are people all around to help you through this. You only have to let someone know you need help.
- The goal after any cancer diagnosis, including CLL, is to get back to normal, but most often, a "new normal" must evolve so you and your loved ones can move forward.
- You must be a self-advocate – or ask someone to advocate for you. You need to be direct in asking for what you need and you need to stand up for your rights to good care and support.
- Taking care of yourself as a caregiver can help you be a better caregiver.

This program from the National Coalition for Cancer Survivorship was made possible by a grant from the United States Centers for Disease Control and Prevention. It is one of many educational programs for cancer survivors, and we invite you to listen to the other programs contained in the *Cancer Survival*

*Toolbox*<sup>®</sup>. They are available at [www.canceradvocacy.org](http://www.canceradvocacy.org) and also available on iTunes. You can download iTunes by visiting [www.apple.com/itunes](http://www.apple.com/itunes) and searching for “Cancer Survival Toolbox.”