# START HERE | FOLLICULAR LYMPHOMA (FL)

RESOURCE GUIDE | FEATURING DR. KAMI MADDOCKS



### **FOLLICULAR LYMPHOMA FACTS**

- Follicular lymphoma has an annual incidence of about 15,000 cases/year in the U.S. with patients having the average age of ~60.
- Diagnostic evaluation includes a physical exam, lymph node biopsy with pathological evaluation, bone marrow biopsy, and imaging.

## **FOLLICULAR LYMPHOMA RESOURCES**

- ACCC
- CancerCare
- Cancer Grace
- Follicular Lymphoma Foundation
- Lymphoma Research Foundation
- Family Reach
- **Cancer Support** Community
  - The Leukemia & Lymphoma Society (LLS)
  - Triage Cancer

### WHAT FOLLICULAR LYMPHOMA PATIENTS NEED TO KNOW

Once diagnosed, make sure you ask your provider what stage (location of lymphoma) and grade (size/shape of lymphoma cells) your follicular lymphoma is:

- Stage I: lymphoma is localized to one general area or organ
- Stage II: is located to one side of your diaphragm
- **Stage III:** is located to above and below the diaphragm
- Stage IV: has organ involved (liver, bone marrow, etc.) involved in a nonadjacent lymph node
- Grade 1 or 2: mostly small round cells and very few big cells
- Grade 3A: large amount of big cells; means it's a more agressive lymphoma than grade 1 or 2
- Grade 3B: largest amount of big cells; more aggressive and treated like a diffuse large B-cell lymphoma (DLBCL)
- Since follicular lymphoma is a slow-growing disease that doesn't develop symptoms quickly, most patients will be stage III or IV.
- If your provider does not know what stage or grade your lymphoma is, ask for a pathologist review. it's important to know this information because it helps determine prognosis and treatment options.
- Don't be afraid to seek a second opinion, particularly from a lymphoma specialist, to make sure you get an accurate diagnosis and possible treatment recommendations.
- For some people, treatment doesn't begin right away and an approach called "watchful waiting," "observation," or "active surveillance" is used to monitor. This usually involves regular visits, lab checks, and imaging scans.
- Work with your healthcare team (which includes your pharmacist, nurse coordinator, patient educator triage nurse, etc.), and care partner to make a treatment management plan.
- Continue to educate yourself about your condition. Ask your healthcare team to recommend credible resources of information.
- Write down your questions before and during your appointments. Bring loved ones to your appointments to help you recall information and to keep track of important details.
- Ask your doctor whether a clinical trial might be right for you.
- Remember that you have a voice in your care. Don't hesitate to ask questions and to share your concerns. You are your own best advocate!

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#### FOLLICULAR LYMPHOMA EXPERT TIPS

START HERE TIP: "If a patient has had a more aggressive behaving follicular or if they've have had a lot of different treatments, that's a time that its good to see if there are clinical trials or if a specialist has anything new or different." - Dr. Kami Maddocks

START HERE TIP: "Ask your doctor: with the treatment you've received, when do you expect to have a regular functioning immune system?" - Dr. Kami Maddocks

**START HERE TIP**: "Patients definitely should be wearing sunblock, because we know that patients with blood cancers can get secondary malignancies." - Dr. Kami Maddocks