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International Waldenstrom's Macroglobulinemia Foundation

2024 Educational Forum

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Second Opinion: The Doctor Will See You Now

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Dennis was diagnosed with Waldenstrom's 6 months ago at the age of 61. He's negative for the MYD88 and CXCR4 mutations. Abnormal lab findings are IgM 3,400 mg/dL, IgG 1100, hemoglobin 11.5, white blood cells 2,000 and neutrophil count 1.4. He was recently hospitalized for pneumonia. His local oncologist has recommended treatment with ibrutinib and rituximab. Dennis wonders if that's the best treatment for him.

Edna is 80 years old and resides in a nursing home. She has a history of high blood pressure and occasional brief episodes of atrial fibrillation. At WM diagnosis, her hemoglobin was 7.5 g/dL, IgM 6200 mg/dL and she' s positive for the MYD88 mutation. She declined chemo-immunotherapy and started on zanubrutinib, achieving a rapid IgM reduction and an increase in hemoglobin. However, because of a severe infection, zanubrutinib was stopped. When she restarted zanubrutinib, she developed persistent a-fib. She continues zanubrutinib with anticoagulation, taking Eliquis (apixaban). Her daughter has asked her to consult with a Waldenstrom expert to be sure she's getting the right treatment.

Marie was diagnosed with Waldenstrom's 5 months ago at age 27. She's currently being treated with bendamustine and rituximab. Below normal neutrophils delayed the 4th infusion for two weeks and her neutrophils are now at the low end of the normal range. She's recently developed thrush and is questioning the need for continuing treatment because she's concerned about immunosuppression, and she's had a very good, partial response to B&R at this point. She's also wondering if she's a candidate for stem cell banking, which her local oncologist hasn't mentioned.

Bob is 58 years old and has a 15-year history of Waldenstrom's. He initially presented with anemia and was found to be MYD88 positive and CXCR4 wild type. He was treated with chemo-immunotherapies in 2007, 2010, and 2011. He was stable following his last treatment with bendamustine until 2020. At that time, he was diagnosed with Bing-Neel syndrome and began ibrutinib. He required a dose reduction due to side effects but was stable until January of 2024. At that time his hemoglobin began falling and in the ensuing months he required two blood transfusions. A CT scan, PET and bone marrow biopsy didn't reveal a more aggressive disease. Ibrutinib was discontinued due to persistent side effects and now he's experiencing withdrawal symptoms. With his hemoglobin continuing to fall and the frequency of transfusions increasing, he is seeking a second opinion.

Roger is a 65-year-old laborer who was diagnosed with Waldenstrom's 2 months ago. He reports increasing low back pain over the past year and an MRI noted several spinal fractures. He has no other medical conditions and has not taken medications predisposing to osteoporosis. His IgM is only 600 mg/dL but β2-microglobulin (6.4 mg/L) and serum albumin (24 g/L) are significantly elevated. His hemoglobin, platelet counts, and LDH are normal. There's no evidence of hypercalcemia. He was positive for MYD88 and TP53; CXCR4 was wild type. He currently complains of persistent pain in his left hip region. An MRI revealed an osteolytic lesion in the left femur. A bone density scan revealed marked osteopenia in both hips and the spine. He's seeking a second opinion to determine the best course of action.

Stanley was diagnosed with Waldenstrom's one month ago at age 59. His mother was diagnosed with WM at the age of 47 and passed away at age 61. He complains of fatigue, lower leg edema, and non-healing leg ulcers. A physical exam revealed enlarged axillary lymph nodes. His bone marrow biopsy detected the MYD88 mutation, a chromosome 6q deletion, and an LPL infiltration of 50%. His IgM is 3,000 mg/dL and IgG 220. Other labs that are out of range include elevated B2M (4.5) and LDH (221). In 2021 he required ICU hospitalization for Covid-19. Another hospitalization was needed for cellulitis in his legs. He's had recent episodes of shingles, atrial fibrillation, and supraventricular tachycardia. His local oncologist recommended he begin bendamustine and rituximab, but he's done a lot of reading online and he's questioning the need to begin treatment.

Julia is 66 and has battled WM for many years. She is MYD88-WT and her IgM has never been higher than 750 mg/dL. She's been treated several times with various combinations of chemo-immunotherapy and is currently on Brukinsa. Her main concern is recurring soft tissue lesions which have been treated with radiation. She would like to know if there is any way to prevent them, how she should be monitored for new lesions and if there are treatment alternatives to radiation.

Ruby was diagnosed with Waldenstrom's 7 years ago at age 74. At that time, her hemoglobin was 9.8 g/dL, IgM 2500 mg/dL, and bone marrow infiltration 80%. She received 6 cycles of dexamethasone, rituximab and Cytoxan and her IgM dropped to 900 mg/dL and hemoglobin increased to 12.6 g/dL. Eighteen months ago, a gradual increase of IgM was noted, and lately, she feels fatigued. Her hemoglobin now is 10.1 g/dL, and her IgM is 2400 mg/dL. Her mutation status is unknown. She would like to repeat the DRC but her local oncologist is recommending ibrutinib so she's seeking a second opinion.

Donna was recently diagnosed with Waldenstrom's at age 66. Her primary symptom is increasing fatigue over the past 6 months. Laboratory studies showed a hemoglobin of 10.2 g/dL and IgM of 2100 mg/dL. A PET scan showed an enlarged heart, thickening of the esophagus, and slightly enlarged mediastinal lymph nodes without skeletal lesions. A bone marrow biopsy showed 5% lymphoplasmacytic cells and amyloid deposition. An abdominal fat pad biopsy was positive for amyloid and additional studies confirmed systemic amyloidosis. She is negative for the MYD88 and CXCR4 mutations. She feels well and seeks a second opinion to learn if she needs treatment right away.

Phoebe was diagnosed with WM and hemolytic anemia in 1997 at the age of 46. A splenectomy resolved the anemia, then a few years later hemolytic anemia returned and was resolved with rituximab. Now, hemolytic anemia appears to have returned as evidenced by her hemoglobin of 7.5, a positive Coombs test, and zero haptoglobin. Her IgM is 150 mg/dL and bone marrow shows no evidence of LPL cells or CD20 markers. She's very fatigued but able to work as a receptionist. Her local oncologist said a BTK inhibitor won't work because she's MYD88-WT and suggests CAR-T cell therapy. She wonders if that's her best option.

James is 56 years old, working full-time in an office and complains of fatigue. He was diagnosed with WM a year ago and he also suffers from rheumatoid arthritis. His hemoglobin is 11.2 g/dL and tests for occult bleeding were negative. A lab workup for the source of anemia found decreased iron, ferritin, and transferrin saturation. His total iron binding capacity and soluble transferrin receptor were increased. His local oncologist is suggesting oral iron supplementation and he's seeking a second opinion to learn if that's the best treatment option.

George is a 74-year-old veteran diagnosed with Waldenstrom's in 2018 and last seen in the clinic 6 months ago. He now complains of hives on his extremities and trunk, increased fatigue, and joint pain. He's lost approximately 10 lbs. without explanation. Upon questioning, he admits to drenching night sweats which have progressively worsened and intermittent low-grade fevers. His labs reveal an increase in IgM from 2500 to 3,000 mg/dL, mild anemia, and low neutrophils. His local oncologist has requested a case consultation to confirm a diagnosis and treatment plan.

Norman is 76 years old and complains of shortness of breath and nosebleeds. His hemoglobin is 8.3 g/dL. He has a history of heart failure and valvular heart disease. Labs revealed a low platelet count of 88, high total protein (13.4 g/dL), and IgM of 8,100 mg/dL and serum viscosity of 4.4. His bone marrow biopsy showed an infiltration of 90%. A CT scan showed increased spleen size and multiple small lymph nodes in the chest and abdomen. His local oncologist, who is unfamiliar with Waldenstrom's, asked for a consultation to determine the best treatment plan.

Thank You!