



HCSP FACT SHEET

HCV ADVOCATE

• EXTRAHEPATIC MANIFESTATION OF HCV •

Waldenstrom Macroglobulinemia

Written by: Alan Franciscus, Editor-in-Chief

Foreword

Waldenstrom macroglobulinemia (WM) is a chronic low-grade type of cancer of the lymph cells. The prevalence of WM in the hepatitis C population is unknown, but it has been found to be higher than in the general population. But WM is considered a rare or uncommon condition in people with hepatitis C. One study among HCV veterans found that out of 146,394 veterans 165 had WM (0.1127095%).

WM occurs when the body produces large amounts of an abnormal protein (macroglobulin) that causes plasma cells to multiply out of control and invade bone marrow, lymph nodes, and the spleen. WM is more common in men than women and among whites than blacks and is more often seen in people over the age of 65.

Important note: Everyone with hepatitis C should be evaluated and receive HCV treatment. Current treatment is very expensive, and some insurance companies and Medicaid/Medicare are restricting HCV treatment to people with the most severe HCV disease. One of the conditions that qualify people for HCV treatment is extrahepatic manifestations. Discuss any symptoms with your medical provider and have them recorded in your medical records. If you are not approved for the drugs to treat hepatitis C, you may qualify for free drugs or co-pay assistance through a pharmaceutical patient assistance program. More information is available at the end of this fact sheet.

Symptoms of WM include:

- Swelling of the lymph nodes, liver or spleen
- Weakness
- Muscle numbness or tingling
- Loss of appetite
- Low grade or mild fever
- Abnormal bleeding
- Fatigue
- Headaches

HCSP FACT SHEET

*A publication of the
Hepatitis C Support Project*

**EXECUTIVE DIRECTOR,
EDITOR-IN-CHIEF,
HCSP PUBLICATIONS**
Alan Franciscus

DESIGN
*Leslie Hoex,
Blue Kangaroo Design*

PRODUCTION
C.D. Mazoff, PhD

CONTACT INFORMATION

Hepatitis C Support Project
PO Box 15144
Sacramento, CA 95813
alanfranciscus@hcvadvocate.org

The information in this fact sheet is designed to help you understand and manage HCV and is not intended as medical advice. All persons with HCV should consult a medical practitioner for diagnosis and treatment of HCV.

This information is provided by the Hepatitis C Support Project a nonprofit organization for HCV education, support and advocacy

Reprint permission is granted and encouraged with credit to the Hepatitis C Support Project.

HCV – Waldenstrom Macroglobulinemia

- Problems with vision
- Kidney problems
- Infections
- Dizziness and/or confusion

Treatment of WM depends on the progression of the disease. The most common treatment consists of chemotherapy. Plasmapheresis (the removal, treatment and return of blood plasma), and monoclonal antibody (Rituxan) have also been used to treat WM, but with varying degrees of success. There are also many drugs in clinical development to treat and manage WM.

References:

- T.P. Giordano et al, Risk of Non-Hodgkin Lymphoma and Lymphoproliferative Precursor Diseases in US Veterans with Hepatitis C Virus, JAMA, May 9, 2007 – Vol 297, No. 18
- *Extrahepatic Manifestations: Non-Hodgkin's Lymphoma (NHL)*, by Alan Franciscus - www.hcvadvocate.org/hepatitis/factsheets_pdf/NHL.pdf

For more information about Extrahepatic Manifestations of HCV check out our Factsheet page

www.hcvadvocate.org/hepatitis/factsheets.asp

For information about WM clinical trials

www.clinicaltrials.gov and type in 'waldenstrom macroglobulinemia'

Related publications:

- **Patient Assistance Programs**
http://hcvadvocate.org/hepatitis/factsheets_pdf/Patient_Assistance.pdf
- **An Overview of Extrahepatic Manifestations**
http://hcvadvocate.org/hepatitis/factsheets_pdf/Extrahepatic.pdf
- **Cryoglobulinemia**
http://hcvadvocate.org/hepatitis/factsheets_pdf/Cryo.pdf

For more information

- | | |
|---|---|
| <ul style="list-style-type: none"> • Americans with Disabilities Act
www.ada.gov • Centers for Disease Control and Prevention
www.cdc.gov | <ul style="list-style-type: none"> • American Cancer Society:
http://www.cancer.org/cancer/waldenstrommacroglobulinemia/ • Waldenstrom Macroglobulinemia at the Mayo Clinic
www.mayoclinic.com |
|---|---|

Visit our websites to learn more about viral hepatitis:

www.hcvadvocate.org • www.hbvadvocate.org
www.hepatitistattoos.org

