Waldenstrom's Macroglobulinemia Patient Profile

Dear WM Patient or Interested Person*:** This survey and database project is sponsored by the International Waldenstrom's Macroglobulinemia Foundation (IWMF) and is being conducted by WM patient volunteers. When you receive this WM Patient Profile (WMPP) form, please make copies, ***give one set to your attending physician and others to individuals that you know that have WM but who are not members of the IWMF. Ask the WM patients to respond and ***encourage your physician to give copies to other patients they may have.***

Purpose of the IWMF and the WMPP Project: IWMF and its related WM Support Groups were founded as an international mutual support group composed of individuals who have WM and their family members. They share experiences, strength, and hope to help each other make each day more meaningful. The WMPP Project evolved from comments at the 1999 Annual Meeting of the IWMF and suggestions from the support groups. Those of us with WM realize that we are quite rare and very little research is being done toward the ultimate cure of WM. We must rely on research and treatment protocols that have been developed for the broader family of Non-Hodgkins Lymphoma disease. The purpose of the WMPP Project is to identify data that will more completely define medical history, diagnosis symptoms and tests, treatment protocols and results, and provide data that can be submitted to medical researchers that will help them in the development of more effective and timely treatment.

Confidentiality - *Patient name and address information will be held in confidence.* Profiles will be assigned a Profile Number and a cross-reference file will be maintained by a designated IWMF official. The general geographic data and all other data will be entered into the WMPP Database, which will be used for analytical purposes, and various reports will be published for the membership and for medical research purposes. In the event we have requests for names of patients for research or related purposes, the requester will be asked to prepare a disclosure form, which would, in turn, be sent by the IWMF to the appropriate members. If the member approves disclosing their unique data and identity, the IWMF would then disclose such information.

Please note, that on Page 6 of the WMPP, there is a disclosure statement that permits you to waive the confidentiality of your unique data and name and address to persons or organizations that the Board of Trustees of the IWMF deems to have a legitimate reason for analyzing the data or contacting you for further information. ***We encourage you to sign the waiver in that it permits the maximum use of the data on a timely basis***.

Patient Deceased? If you were a caregiver or otherwise involved with a patient who is now deceased, ***do not use this form***. If you are willing to complete a form for the deceased patient write or e-mail Jim Johannsen at the address shown on bottom of Page 6 and we will send you a slightly different form to complete.

PLEASE PRINT CLEARLY and USE THE INSTRUCTIONS IN EACH SECTION TO GUIDE YOU

....If you don't have all the information requested, submit whatever you have. If space is too limited elaborate on separate page....

A. Identification Data: Instructions: Self-explanatory.

Name _____ Male _____ Female _____ Date of Birth _____

Address _____ Place of Birth (City/State/Country) _____

City _____ State/Prov. _____ Country _____ Postal Code_____

Phone _____ E-Mail _____ FAX _____

Racial and Ethnic Background _____

B. Family Medical History: Please identify your family members (other than self) who have had the following illnesses:

Waldenstrom's	_____	_____	_____	_____	_____
Multiple Myeloma	_____	_____	_____	_____	_____
Lymphoma	_____	_____	_____	_____	_____
Leukemia	_____	_____	_____	_____	_____

Other cancers or major illnesses in the family such as diabetes, heart disease, etc. (Specify cancer type or illness & family member):

_____

_____

_____

C. Patient Medical History (Pre-WM Diagnosis): Instructions: Circle the following codes to identify all your major illnesses and elaborate on those and any others in the spaces below:

1 = Heart and Circulatory System	5 = Respiratory System	9 = Visual
2 = Immune System	6 = Digestive System	10= Hearing
3 = Brain and Nervous System	7 = Bones, Joints, Muscles	11= Periodontal Disease
4 = Emotional/Mental Health	8 = Reproductive System	12= Pneumonia

_____

_____

_____

_____

What is your blood type? (Include RH Factor+/-)_____ Ever give blood (Yes or no)? _____ **C11** Received blood (Yes or No)? _____

Elaborate on nature of blood donations or receipt: _____

_____

Provide any other data you feel is pertinent:_____

_____

_____

D. Patient Occupational, Geographical, Environmental, and Lifestyle History: Instructions: See each sub-section below.

Occupations: Identify with your ages for each: _____ _____

_____ _____ _____

Geographical regions you lived in: List the US States and/or areas of the world where you have lived with your ages for each:

_____ _____ _____

Type of areas you lived in Use the following codes for the types of areas you lived in during the listed age periods:

1 = City	3 = Rural town	5 = Industrial area	
2 = Suburb	4 = Agricultural area	6 = Other (Where?)_____	
_____All my life	_____Age 21 to 30	_____Age 41 to 50	_____Age 61 to 70
_____Age 0 to 20	_____Age 31 to 40	_____Age 51 to 60	_____Age 71 and over

Environmental exposures Use the following codes for environmental conditions you believe you had excessive contact with during the listed age periods (elaborate below or on a separate page):

1 = Chemicals	4 = Radiation	7 = High Voltage power lines	
2 = Carcinogens	5 = High Air pollution	8 = Other	
3 = Pesticides	6 = High Water pollution	_____	
_____ All my life	_____ Age 21 to 30	_____ Age 41 to 50	_____ Age 61 to 70
_____ Age 0 to 20	_____ Age 31 to 40	_____ Age 51 to 60	_____ Age 71 and over

History of smoking: Have you ever smoked (yes or no)? _____ Do you smoke now (yes or no)? _____ If yes, amount per day? _____

If you smoke now or have smoked, what age did you begin smoking? _____ Age you quit smoking? _____ When quit, amount per day? _____

Alcohol use: Have you ever used alcohol? (Yes or No) _____ If you drink alcohol now, enter oz. per day _____ or ml. per day_____

If you drink alcohol now or have ever, age you began alcohol? _____ Age you quit alcohol? _____ Quit oz. per day _____or ml. per day _____

Other Possible Lifestyle and Environmental Influences: (Elaborate)

_____

_____

_____

_____

E. Diagnosis Information: Instructions: For each symptom, circle the degree of symptom in the "At Diagnosis" column ,then circle the degree of symptom in the "Symptoms Now" column "S" for strong, "M" for moderate, "W" for weak, "N" for none.

Symptoms:	At Diagnosis	Symptoms Now	Symptoms:	At Diagnosis	Symptoms Now
1. Fatigue	S M W N	S M W N	17. Frequent Colds	S M W N	S M W N
2. Weakness	S M W N	S M W N	18. Chronic Cough	S M W N	S M W N
3. Anemia	S M W N	S M W N	19. Headaches	S M W N	S M W N
4. Lethargy	S M W N	S M W N	20. Shortness of Breath	S M W N	S M W N
5. Depression	S M W N	S M W N	21. Shingles or other Rash	S M W N	S M W N
6. Loss of Appetite	S M W N	S M W N	22. Nose Bleeds	S M W N	S M W N
7. Lack of Concentration	S M W N	S M W N	23. Ache in Shoulder, Arm or Back	S M W N	S M W N
8. Hallucinations	S M W N	S M W N	24. Leg Cramps	S M W N	S M W N
9. Insomnia	S M W N	S M W N	25. Hot, Cold or Swollen Feet	S M W N	S M W N
10. Allergies	S M W N	S M W N	26. Muscle Ache	S M W N	S M W N
11. Weight Gain	S M W N	S M W N	27. Arm/Leg Numbness	S M W N	S M W N
12. Weight Loss	S M W N	S M W N	28. Blurred Vision	S M W N	S M W N
13. Fevers	S M W N	S M W N	29. Cataracts	S M W N	S M W N
14. Night Sweats	S M W N	S M W N	30. Soft Finger or Toenails	S M W N	S M W N
15. Enlarged Lymph	S M W N	S M W N	31. Hair Loss or Change	S M W N	S M W N
16. Enlarged Liver, or Spleen	S M W N	S M W N	32. Peripheral Neuropathy	S M W N	S M W N
35. Nausea	S M W N	S M W N	33. Incessant Itching	S M W N	S M W N
36. Bleeding Gums	S M W N	S M W N	34. Rash on Legs	S M W N	S M W N

Other Symptoms: _____

_____

_____

Month and Year of Diagnosis:_____ How many years do you think you had WM before diagnosis? _____

Circle one of the following codes that identifies what first led you on the path to being diagnosed with WM:

52 = Routine physical
53 = Blood Test for other reasons
54 = Symptoms leading to diagnosis
55 = Other WM patient advise
56 = Other Illness or disease visit
57 = Previous diagnosis of Chronic Fatigue Syndrome
58 = Do not know
59 = Other (Explain _____
_____

Describe your diagnosis sequence process: _____

_____

_____

_____

Describe any unusual or speculative factors that you or your doctors may feel are relevant to the cause of your WM or the diagnosis:

_____

_____

_____

_____

_____

F. Treatment History: Instructions: For all treatment questions please use the following codes:

Treatment Codes:

1 = No treatment (Watchful Waiting)
2 = M2 Protocol
3 = Colony Stimulating Factors (Epogen, Erythropietin, Procrit,etc.)
4 = Chlorambucil (an alkylating agent, ie. Lukeran, etc.)
5 = Cytoxan (an alkylating agent)
6 = Other alkylating agent (Specify)_____

_____

7 = 2Cda (a nucleoside analogue)
8 = Fludarabine (a nucleoside analogue)
9 = Other nucleoside analogue (Specify)_____

_____

10 = Rituxin
11 = Interferon
12 = Bone Marrow Transplant
13 = Stem cell transplant
14 = Vincristine
15 = Plasmapheresis
16 = Prednisone
17 = Other: (Specify)_____

Codes for **Years** that treatment was effective

0 = Less than a year
1 = 1 to 2 years
2 = 2 to 3 years
3 = 3 to 4 years
4 = 4 to 5 years
5 = 5 to 6 years
6 = 6 to 7 years
7 = 7 to 8 years
8 = 8 to 9 years
9 = 9 Years or more

Side Effects (below): Use the numbers for **Symptoms** in Section E for any side effects you experienced from **treatment, not your continuing symptoms.**

Note for Treatment Codes: If you had any **combination treatments**, show both in the boxes below, such as 7/10.

Treatment Regimens: Instructions: For your Treatment sequence below, a regimen is from the beginning date until that treatment has been concluded. Side effects are from treatment only, not your continuing symptoms.

For your first regimen**,** enter the appropriate month/year and enter "continuously" if applicable

Dates, from _____to_____ Treatment code(s)_____ Year's code _____ Side effects codes_____

For your second regimen**,** enter the appropriate codes for:

Dates, from _____to_____ Treatment code(s)_____ Year's code _____ Side effects codes_____

For your third regimen**,** enter the appropriate codes for:

Dates, from _____to_____ Treatment code(s)_____ Year's code _____ Side effects codes_____

For your fourth regimen**,** enter the appropriate codes for:

Dates, from _____to_____ Treatment code(s)_____ Year's code _____ Side effects codes_____

For your fifth regimen**,** enter the appropriate codes for:

Dates, from _____to_____ Treatment code(s)_____ Year's code _____ Side effects codes_____

If you have had more than five regimens of treatments, please **put a check mark here** _____ and indicate the sixth and successive regimens of treatment in the above format on the blank page and attach to this form set. Please use the same format as the first five treatments. ***Be sure to enter your most recent regimen of treatment.*** The last entry you make should be your most recent treatment.

Describe any other factors that you or your doctors may feel are relevant to your disease, treatment and response to treatment: (Lab test data is covered in the next section).

_____

_____

_____

_____

_____

_____

Your Attending Physician: Name_____

Address:_____City_____State/Prov._____

Country_____ Postal Code_____Phone_____E-mail_____

G. Laboratory Test Data: Instructions: There are many more tests that are taken for WM Patients than we can accumulate data on but the nine listed in this section seem to be the most common. If you want to report others, clearly enter the test and readings on a separated page.

At the time of your **diagnosis** enter the date of your lab tests (month and yr) and your lab readings –

Date _____ IgM _____ IgG _____ IgA _____ SV _____ WBC _____ RBC _____ HGB _____ Platelets _____ Lymphocytes %_____

Prior to your **first regimen** of treatments enter your -

Date _____ IgM _____ IgG _____ IgA _____ SV _____ WBC _____ RBC _____ HGB _____ Platelets _____ Lymphocytes %_____

6 months after completion of **first regimen** of treatments your -

Date _____ IgM _____ IgG _____ IgA _____ SV _____ WBC _____ RBC _____ HGB _____ Platelets _____ Lymphocytes %_____

Prior to your **second regimen** of treatments enter your -

Date _____ IgM _____ IgG _____ IgA _____ SV _____ WBC _____ RBC _____ HGB _____ Platelets _____ Lymphocytes %_____

6 months after completion of **second regimen** of treatments enter your -

Date _____IgM _____ IgG _____ IgA _____ SV _____ WBC _____ RBC _____ HGB _____ Platelets _____ Lymphocytes %_____

Prior to your **third regimen** of treatments enter your -

Date _____ IgM _____ IgG _____ IgA _____ SV _____ WBC _____ RBC _____ HGB _____ Platelets _____ Lymphocytes %_____

6 months after completion of **third regimen** of treatments enter your -

Date _____ IgM _____ IgG _____ IgA _____ SV _____ WBC _____ RBC _____ HGB _____ Platelets _____ Lymphocytes %_____

For your **most recent blood work** enter your:

Date _____ IgM _____ IgG _____ IgA _____ SV _____ WBC _____ RBC _____ HGB _____ Platelets _____ Lymphocytes %_____

Have you ever had a **CAT scan**? Yes _____ No _____ If regular, how often? Every 3 months _____ Annually _____ Other _____

H. Ongoing Treatment for Other Illnesses, Vitamin Routine, Alternative Medicine, and Exercise Program: Instructions: Self Explanatory

Do you take daily multiple vitamins and/or minerals (yes or no)? _____ Other Vitamins and/or minerals? (Indicate which and dosage and frequency_____

_____

Do you take any alternative medicines (yes or no)? _____ List them with quantity and frequency_____

_____

Do you exercise on a regular basis (yes or no)? _____ How often per week? _____ How long per session_____

Type of exercise(s) you do? _____ _____ _____ _____ _____ _____ _____

1 = Walk
2 = Run
3 = Aerobics
4 = Calisthentics
5 = Hand or leg weights
6 = Treadmill
7 = Weight Machine
8 = Sports (Name)_____
_____
9 = Other (Describe)_____
_____

Do you feel any other treatment/activity you do is important in your control of WM? (Describe) _____

_____

_____

_____

_____

_____

I Present Status of Health: Instructions: Self Explanatory

Are you being treated for medical problems other than WM? If so, elaborate_____

_____

_____

_____

_____

_____

_____

_____

Rate the quality of your life at the present time: Excellent _____ Very Good _____ Good _____ Fair _____ Poor _____ Very Poor _____

J. Remarks (add any comments that you feel are appropriate) Instructions: Enter in this section anything that you feel may be relevant to accumulating data about WM. Let your imagination take over and give us your ideas, emotional feelings, success and/or failure stories or anything else you want to say.

_____

_____

_____

_____

_____

_____

Confidentiality Waiver: I have read the Introductory Statement on page one regarding confidentiality, and I desire to make this WMPP data available for the broadest use possible and I therefore waive the confidential nature of my unique data and my identification. The IWMF has my permission to disclose any and all of this information to individuals or institutions that the IWMF Board of Trustees and/or the Scientific Advisory Committee feel have a legitimate reason to analyze the data and/or communicate directly with me.

Only the Patient **can sign here to waive confidentiality_____Date_____**

Name of next of kin's name_____ If address is other than patient or person submitting form, specify.

Name and relationship of person submitting this WMPP _____Patient ____ Spouse ____ Caregiver____ Other (Specify)_____

If person completing this form's address is other than that on page 1, please enter below:

Address_____ City_____ State/Prov _____ Country_____ Postal Code_____

Phone_____ E-Mail_____ FAX_____

******** ***Please Keep a Copy of the Entire WMPP in Your Files for Future Reference*** ********

Direct any questions to E-mail address of anyone on the WMPP Cmttee:

Eddy Anderson – E-mail – eddyanders@aol.com - Port St. Lucie, FL
Lynn Bickle – E-mail – flb@email.msn.com - Thousand Oaks, CA
Bob Haliwell - E-mail – rah@inreach.com - Groveland, CA
Barb Hauser – E-mail – hauserb@baydenoc.cc.mi.us - Escanaba, MI
Jim Johannsen – E-mail – johannsenj@aol.com - Santa Barbara, CA

Return this Profile and any supplemental information to:

James H. Johannsen, Chair, IWMF WMPP Project
P. O. Box 6434
Santa Barbara, CA 93160-6434

Please be sure you have completed all six pages and submitted any necessary pages with additional info.

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