Haematology Hospital & Community Liaison Booklet









Hématologie clinique et thérapie cellulaire

This booklet belongs to :





Mademoiselle, Madame, Monsieur,

Y ou have just come under our care for the diagnosis and treatment of a haematological illness. You will be offered a specific treatment adapted to your case, which will be explained to you by word of mouth. For all that, being told of the diagnosis of your illness and of its treatment by a medical and care team, in a framework you are not familiar with, can give rise to questions and anxieties. So we have put together this booklet to answer in some measure questions that it is normal for you to ask.



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This booklet has been given to you because we have programmed your case to be supervised in outpatient appointments. But it is possible that at a certain point in your treatment you will be offered attendance at the day hospital, or even full admission to hospital. In that case you will be given a patient book more suited to a more hospital-based care process.

The purpose of this booklet is to present to you:

- The medical and care teams,
- Various bits of information about your care that will depend on your illness, the stage it has reached, its seriousness, but also on your age and medical history,
- The help which may be put at your disposal or that of those near to you, in your capacity as a user of the health system,
- Patient associations specialised in your illness, with whom you can share your experiences, and who can also be an alternative source of information.

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This liaison booklet has been designed by a multidisciplinary piloting committee in accordance with the national recommendations of the Cancer Plan.

Its purpose is to bring together information about your illness, you care, and any treatments you receive and to communicate them to your **GP** and the health professionals who provide your care at home.

This booklet is yours, don't hesitate to pass it to anyone involved in your ongoing care. It serves as a link between the Haematology Department in the Limoges CHU or the health establishments associated, and where you live - your home, or residential care home, etc.

This booklet will enable each health professional to intervene with greater effectiveness and knowledge of the situation at any given moment in your ongoing care. For us it is a measure of quality. In the years to come the *MOVE TOWARDS OUTPATIENT CARE* which exists at present will intensify. It is important for you to be able to familiarise yourself with your illness and get to recognise its symptoms as well as potential side effects of your treatments. Those looking after you will coordinate themselves around you, and this booklet is a link for all, and an essential means for everyone to keep each other informed. It also contains numbers for you to call in case of difficulty.

Remember to bring this booklet with you when you visit your GP, nurse, physiotherapist when you are at home. Bring it with you for consultations with your family doctor, the various specialist doctors, including your pharmacist and show it to your haematologist to be updated if need be.

Do not hesitate to ask people caring for you to note down any problems or questions that you encounter throughout your treatment on the pages marked "Notes and Messages".

This booklet is not a medical record but it contains data that is precious to its owner. If you find it, please return it " à l'attention des infirmières (IDE) coordinatrices du parcours de soins au centre de coordination en onco-hématologie le 3CR-H or by ringing the coordination nurses on the freephone number: 0 800 54 32 20.

Information about the medical team

In addition to this booklet, you may be given other brochures or documents to explain your specific illness, additional tests, treatments, such as chemotherapy, and support care. This might include information on growth factors or pain treatment. for instance.



Information in this booklet serves only to complete the explanations that you are given orally by your doctors and those looking after you. Please feel confident that we are here to listen to you and answer your questions.

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Do not forget that the best way to get explanations is to ask the questions you want answers to.



- In the Clinical Haematology and Cellular Therapy Department of the Limoges CHU you will be looked after by a medical team made up of various doctors who can work together on your care path in keeping with you diagnosis and the ways in which you are to be treated. The haematology team is made up of Doctors Julie Abraham, Natalia Dmytruk, Stéphane Girault, Marie-Pierre Gourin, Arnaud Jaccard, Céline Kennel, Stéphane Moreau, Amélie Penot, Liliane Remeniéras, Mohamed Touati and Pascal Turlure, aided by a head of clinic and interns, young haematologists in training.
- You may be followed up subsequently in outpatients by the doctor you met at the time of your diagnosis. He will be your "médecin hématologue référent", the haematologist in charge of vour case.

And do not forget that your GP remains the pivotal point in your ongoing care. He will support

you throughout your care in collaboration with your haematologist. Communication between the GP and the hospital is normally via hospital letters, and you can have a copy of these on request. These letters may be dictated at the time of your consultation and in your presence. Ask your GP to provide for your treatment to be covered 100%, as your diagnosis gives you the right to this.



For any complex or urgent situation, your GP will have the out-of-hours number of the department to help him with your care either through specialist advice given over the telephone or in a book of specific advice called

Hémato-guide



Don't forget that he is your first recourse in relation to your illness and he will be best placed to advise you and to obtain any necessary specialist advice

Information About the care team

The organisation of your ongoing care may result in your meeting a succession of different State Registered Nurses (called Infirmières Diplômées d'Etat (IDE) here) as well as other health professionals to whom you and those close to you may have recourse.

You meet coordination nurses :

To assist you when you are told of your diagnosis, to assess your potential weaknesses if you are elderly, to help you to understand your treatment and to organise and adapt your daily life at home, your family life and the sports you practice to the constraints and possible risks caused by the illness and its treatment.

You will meet Corinne Bourdeix, Catherine Granet, Diane Tilmant-Tatischeff, etc.



Your coordinating nurse is tasked with supporting you when you are told of the diagnosis, by being present at the appointment at which you are given the medical diagnosis of your illness. If need be, she will go into greater detail about the medical explanations of the illness and the treatment you are to receive for it, and provide you with a copy of this *liaison booklet* and if appropriate, a *Personalised Care*

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Plan (Plan Personnalisé de Soins (PPS)). She will decide with you on any aid that you might need to best support you through your illness.

She will introduce you, as needed, to the dietician, the psychologist and the social assistant. She will help you fill in any documents relating to your care, so that more is known about your allergies, the other medication you take, your life style or to appoint a person of confidence. Do not hesitate to communicate to the care team any thoughts you have about your fight against the illness, the values that are important to you and how to draw up your advance directives. The State Registered Nurses will draw up with you a list of contact details for all the medical resources whether or not they provide care, who will form a hospital/community link around you as you face the illness.

You will be told of all the sources of help you can have recourse to if you have questions or in case of emergency.

Any particular precautions to take at home and any advice about the life you are used to leading will be explained to you at information sessions, and if necessary by a personalised phone call to you at home a few days later.

If necessary, the coordinating can contact those you choose to care for you at home and your pharmacist.

A pharmacist from the CHU

can meet you to ask about your usual medication and explain again how to take the treatments prescribed for you, and what to do if you forget, or if you are sick etc., and will give you advice to help you tolerate them as well as possible. Do not hesitate to mention to him all the medication you take regularly or at different times, whether they be prescribed by your GP or the various specialists or whether they are ones you buy for yourself. It is important for him to be able to check for any incompatibilities between the medication prescribed for your blood disorder and that prescribed for other illnesses. Do tell him also if you have a tendency to forget to take your medicine from time to time, as he can help you by providing a pill box or a carer to visit you at home, in collaboration with your local pharmacy or your regular GP.



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Professionals In support care

Psychologists :

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Will place themselves at your disposal from the very beginning of your care.

Being told you have a malignant blood disorder is a quite legitimate source of anxiety and often wakes old difficult memories for all patients but also for those around them. You can meet a psychologist by simply asking or on the advice of those looking after you. Moreover, if you or someone close to you want to consult a psychologist working in the community, you can benefit from up to six free sessions, the cost being covered by the regional independent psychologists' network (le réseau régional des psychologues libéraux) :



PSY-HEMATOLIM Tel. : 05 55 05 60 63

Do not hesitate to contact them when you are going through difficult times for you and your family. Tel. : 05 55 05 66 72

A Dietician :

Is also at your disposal if risks or signs of malnutrition are detected by those caring for you. It is important to prevent malnutrition during your treatment as it can easily give rise to complications.

Nutritional care may be recommended for you either at a medical appointment, when you would be seen by a dietician from the department, or at home, where you would be visited by an independent dietician. Advice about your diet, nutritional supplements to take in addition to your ordinary food, or more intensive care may prove necessary.

Free consultations in your own home with independent dieticians

Can be offered to you as a result of a partnership between the LINUT network and the HEMATOLIM network. To get in touch with the dietician, speak to your haematologist or the coordinating nurse or directly to the dietician, who can give you an appointment or ring the switchboard on 05 55 05 55 55, and ask for extension 54857 or 49835.



The hospital also offers non-medical support



Froma sophrologíst

Relaxation with an experienced sophrologist may help you get back your energy and bring you a feeling of well-being during difficult moments in your illness. These techniques can also be effective after a period of training at home so that you can use them regularly even when she isn't there.

Michèle Zygar is in the department on Mondays from 10am to 3.30pm, Tuesday afternoons, all day Wednesday and on Fridays from 10am to 3.30pm.

By a beautícían

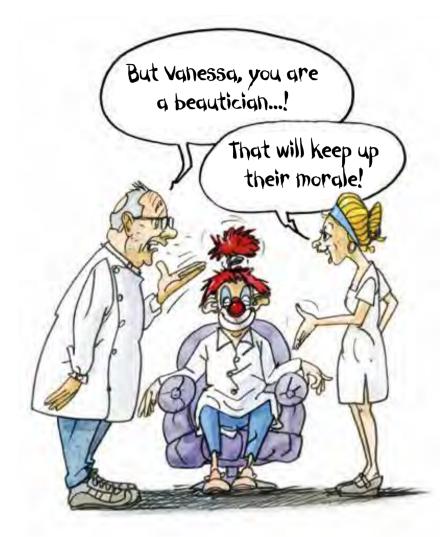


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Aesthetic advice, relaxing body treatments carried out by a beautician trained in the care of patients may be offered you by appointment to help you keep or regain your self image and give you a feeling of well-being. You may be given advice in keeping with requirements due to the possible depression of your immune system about the care of your skin and fingernails during your treatment. Séverine Aupetit is in the department on Mondays and Tuesdays and alternate Thursdays.





Do not hesitate to ask for an appointment to relax and increase your feeling of wellbeing

Either by contacting the nurses or psychologists in the department or by contacting La ligue contre le cancer.

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A Social assistant

When a blood disorder arises, it is often necessary to reorganise one's professional and social life for a variable length of time.

From the time you learn of your diagnosis you can take an overview with the social assistant about your needs for social, material or even financial or professional help that your illness may give rise to.

For example :

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- Possible difficulties around care of your children or of a near one you are responsible for,
- Sickness leave or the adaptation of your working hours or Going back to work,
- The organisation et possible adaptation of your home in collaboration with the medical and care team and carers to find the most appropriate solutions: the equipment needed or the work that needs to be carried out, in collaboration with your insurers.
- An on-going loan or financial difficulties : a request can be made if necessary to the Ligue contre le cancer for patients who encounter difficulties in getting financial help.



Do not hesitate to call on us if your situation changes in the course of your treatment where putting help in place is concerned.

Tél. : 05 55 05 60 11

For older patients Care that is specific and appropriate to them

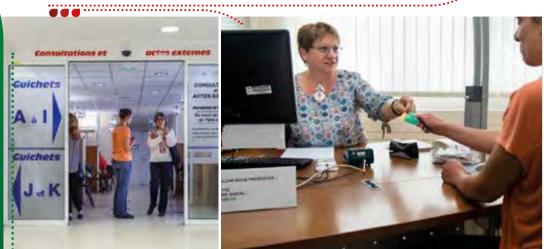
Pretty strong for an old boy! For older patients, a qualified team specially trained in the care of blood disorders at an advanced age, made up of specialist doctors and nurses will meet you to assess with you the risks linked to the fragilities resulting from increasing functional impairment after a certain age.

> Beyond the age of 70 we do not all age in the same way, and this shows in different ways in different people. It is therefore very important, even if you are fully fit, to assess the degree of spontaneous risk that could be aggravated by the illness and its treatments by using a short geriatric screening process.

The objective of this assessment will be to seek out potential areas of risks of weakening and prevent them by offering a treatment matched and graduated to the individual patient, without for all that depriving him of chances to get better. A nurse will carry out a quick ten-minute assessment and will if need be refer you to a geriatric doctor for a complete assessment leading to a special regime being put in place for your treatment and its follow-up.



Administrative information



How to fulfil the administrative formalities properly

Have someone close to you come with you !!!

On your arrival, you need to register at the entrance to the hospital at the admin office on the ground floor labelled "consultations externes", So as to obtain a "feuille de consultation externe" - a document full of sticky labels.

Have ready the following administrative dpocuments:

- ∎ ID,
- carte vitale,
- attestation d'assurance et de mutuelle.

Have ready documents useful for your care:

- A list of your medication or your GP's prescriptions and those of your local specialists,
- Your X-rays or blood tests carried out in advance of the appointment This liaison booklet,
- Your personalised care plan (PPS) which you were given at the appointment when you were told the diagnosis.

Gather together and store the important elements of your diagnosis (biopsy results or other results), and of your on-going care (results from your NFS or from protein electrophoresis) along with copies of your prescriptions.

Your outpatients appointment is on the 8th floor lift B.

All the haematologists in the department have several weekly appointments in an area that is shared with other specialisms. A care assistant will greet you on arrival. Three nurses carry out the blood tests and the prescribed tests at the time of the appointment.



Do not leave until you have been given your next appointment, even if it is a very long way ahead, in keeping with the time decided by the doctor and your own availability during this period. That will prevent you wasting time on the phone calling for an appointment. However, if something prevents you attending, please warn us at least 24 hours in advance on 05 55 05 66 52 so this appointment can be used by someone else.

Outpatients in haematology is available daily from different haematologists.

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Outside regular consultation times, emergency consultations are carried out by the on-call doctor at the phoned request of a GP:

on 05 55 05 66 42 (from 8am to 5pm) and on 05 55 05 67 55 (after 5pm).

For follow-up appointments, prepare a list of your questions, a resume of important events that have happened since your last visit to hospital, the results and counts of your regular tests, and note the treatments you are taking. Do not forget to notify us of any changes in your ID, your address change or your GP.

The stages in your Care path

From the moment of diagnosis onwards your will be guided through various key moments during which we will support you with a multidisciplinary team in accordance with the recommendations of the national Cancer Plans.

How the diagnosis is given (measure No 40 of the national cancer plan)

To help you cope better at the beginning of treatment for your illness, telling you about your diagnosis is done in four stages:

- The medical appointment at which the consultant will tell you your diagnosis when the doctor tells you about your illness and the further explorations necessary to refine the diagnosis, or the factors relating to your prognosis, or how they propose to treat you for it.
- The consultation with a nurse, which is a time for support and to work out your needs.
- The working out of the support care needed for you to have the best care. For instance, it may suggested that you meet various professionals such as a psychologist, a dietician, a social assistant, a sophrologist, a beautician, a physiotherapist etc.,.
- A time for liaison between the hospital and community health providers This will be organised with those who look after you in the community in keeping with your illness or your treatment - family doctor, your usual pharmacist, or nurse etc.

At this meeting, be sure to have someone go with you and do not hesitate to ask any questions you have about your illness and its treatment

The multidisciplinary meeting (RCP).

With your permission, your medical notes will be discussed by a multidisciplinary team made up of haematologists and the various specialists who have been involved in your diagnosis or in the assessment of your case in order to offer you the most appropriate treatment, in line with your illness, and your risks in accordance with national and international benchmarks. Different RCPs depending on which pathology is being discussed meet weekly at the Limoges CHU under the responsibility of



the Centre de coordination régional d'hématologie du Limousin (3CR-H).

The proposed treatment that results from the discussion as well as the rational in terms of risk/benefits will be presented to you in a programmed meeting with the haematologist you have been referred to.

It is an important moment in the doctor/patient relationship that cannot take place over the phone. So there is no point is ringing up to know the result ahead of the meeting.

For this appointment you are recommended to have someone close with you. Unless there is an emergency do not hesitate to ask for time to think about it, or for a second opinion if that seems to you to be necessary. It will not harm your relationship with the doctor.

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Your family doctor will receive these treatment proposals and can explain them to you in different words. So do not hesitate to consult him as well.

A personal Care Plan (Un Plan Personnalisé de Soins (PPS)) will be drawn up with you, to schedule the principal stages of your care path, with a provisional calendar showing your treatments, a regular assessment of your tolerance of them and of their effectiveness or simple follow-up.

Policy of quality in the service of the patient

The Clinical Haematology and Cellular Therapy Department has for a long time committed itself to quality. The care staff are as a team committed to improve the information you are given and the quality and safety of your care throughout your illness and to support your care at home.

A number of information booklets have been put together for you to read. Do not hesitate to ask for them.



Recognition of this culture of quality has enabled the department

 To obtain in 2016 the European JACIE¹ accreditation for action taken in haematopoietic stem cell transplants aimed at promoting excellence in the care of transplant patients,

Numerous regional or national prizes for quality*

- le Prix de la Société Francaise d'Hématologie for work on Amylose AL, le prix RJ Zittoun de la Société Française d'Hématologie in Paris in 2011 for quality of support of patients,
- Ie prix de la Fondation de France at Nantes in 2008 for support of end of life patients,
- le prix de la Société européenne de greffe de moelle (EBMT) à Milan en 2014 for the transplant patient's information manual.
- nomination for Victoires de la Médecine for the organisation of the HEMATOLIM network etc.

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JACIE : Joint Accreditation Committee-ISCT & EBMT (International and European societies for bone marrow and haematopoietic stem cell transplants)

Covering the catchment area with the HEMATOLIM network

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The purpose of the HEMATOLIM network is to combat inequality of access to care and to therapeutic innovation for patients with malignant blood disorders within the Limousin area. The HEMATOLIM network, integrated in the ROHLIM² network was accredited by l'INCa^{*} in

November 2011. It tasked itself with:

Providing for advanced consultant appointments with specialist haematologists by

Drs M. TOUATI, A. PENOT et S. MOREAU in various hospitals in Limousin,

- Training health professionals brought together into a network of specialist haematological care.
- Coordinating your care to support treatment in your own home, working with the HAD structures or in hospitals closest to where you live.

- organising chemotherapy at home, alternating with day hospitals in complete safety thanks to the arrangement called l'Externalisation et la Sécurisation de Chimiothérapie injectable à Domicile pour les Hémopathies Malignes (ESCADHEM) which won the CPAM³ de la Haute-Vienne prize in 2012,
- offering, at no cost to the patient, 6 consultations with psychologists working in the community for you or those close to you if you have problems, in the framework of a fee exemption through the PSY HEMATOLIM procedure,
- offering, at no cost to the patient, support from dieticians, in partnership with the LINUT⁴ network,
- connecting with the UCOG-Hélim⁵ for oncogeriatric care offered by Drs JB. FARGEAS, N. SIGNOL et M.A. PICAT.

With close regular links with the reference site Limoges CHU, health professionals from the various hospitals and clinics provide for your follow-up by making available, according to where they are based, consultations, chemotherapy, transfusions or support care.

For more information Contact the network coordinator Mme E. Dumond-Wibaux on 05 55 05 89 40 Or her secretary on 05 55 05 60 63.

² ROHLIM : Réseau d'Onco-Hématologie du LIMousin ³ CPAM : Caisse Primaire d'Assurance Maladie ⁴ LINUT : Réseau LImousin de NUTrition
 ⁵ UCOG-Hélim : Unité de Coordination Gériatrique d'Hématologie du LIMousin

Haematology Consultations away from the CHU

- 87 Centre Hospitalier de Saint-Junien consultations with Dr M. TOUATI weekly each Tuesday morning.
 (Secretary Mme DESSOLA Tel.: 05 55 43 50 06 / fax: 05 55 43 50 82)
- 87 Centre Hospitalier de Saint-Yrieix-la-Perche consultations with Drs J-B. FARGEAS et B. VIGNERAS and presentation of cases to the RCP. (Secretary - Tel. : 05 55 75 75 20 / fax : 05 55 75 76 62)
- 87 Centre Hospitalier de Bellac consultations with Dr M. TOUATI one Wednesday afternoon a month in en collaboration with Dr J. THEVENOT. (Secretary Mme RAPIN - Tel. : 05 55 47 20 03 / fax : 05 55 47 20 37)
- 87 Clinique Chénieux consultations with Dr M. TOUATI every fortnight in collaboration with the rheumatology team: Drs J. VAQUIER et D.COYRAL. (Secretary Mme COIFFARD-ROCHER Tel.: 05 55 45 44 44 / fax: 05 55 45 44 45)
- 19 Centre Hospitalier de Brive : Dr S. LEFORT, haematologist et le Dr E. KFOURY.

(Secretary Mme ROSE - Tel. : 05 55 92 60 52 / fax : 05 55 92 60 77)

19 - Centre Hospitalier de Tulle consultations with Dr M. TOUATI, fortnightly on Friday morning in collaboration with Dr M. GHICA.

(Secretary Mme MARTIN - Tel. : 05 55 29 79 71 / fax : 05 55 29 86 36)

- 19 Centre Hospitalier d'Ussel consultations with Dr S. MOREAU, fortnightly on Tuesdays in collaboration with Dr. M.P. NORD-ROUBY. (Secretary Mme PONS - Tel. : 05 55 96 43 21 / fax : 05 55 96 42 03)[^]
- 23 Centre Hospitalier de Guéret consultations with Dr A. PENOT, every Wednesday in collaboration with Dr D. DEVESA and and presentation of cases to the RCP.

(Secretaries Mmes ROQUE et VIOLA Tel. : 05 55 51 87 20 / fax : 05 55 51 48 85)

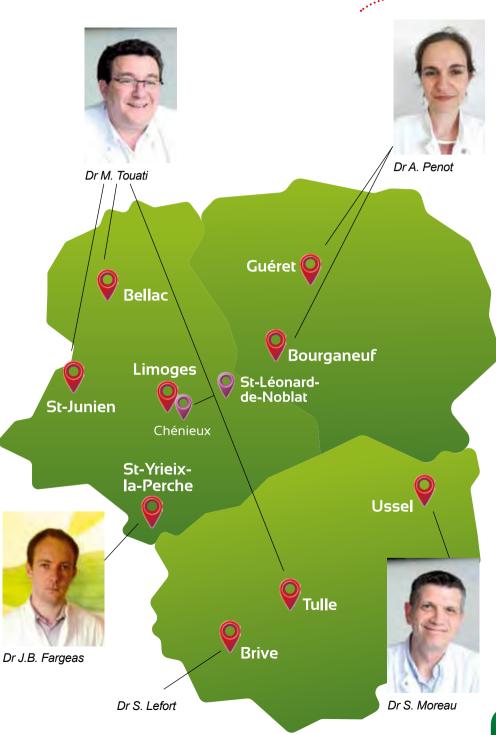
Some hospitals take part in the hospital-based oncohaematological follow-up care without specific consultation times:

87 - CHU Service de médecine de suite de l'hôpital Jean Rebeyrol with Dr C. SOL-TOUATI

(Tél. : 05 55 05 65 20 / fax : 05 55 05 65 12)

87 - Centre Hospitalier de Saint-Léonard courtesy of the GPs at Saint-Léonard with Dr MATONNAT

(Tel. : 05 55 56 43 00 / fax : 05 55 56 43 22)



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Clinical Research : An essential stage

Improvements in knowledge about illnesses and their treatments are the fruit of medical research that a large number of patients ave contributed to. In your turn, you may be offered, depending on the nature and stage of your illness, an opportunity to take part in a clinical trial.

Your participation in a trial will only happen after you have been briefed on its purpose, the changes involved by the protocol as compared with the usual treatment, in terms of hypothetical risks and benefits, or additional blood tests, outpatient appointments or even hospital admissions that might be necessary.

The recording of your agreement in full knowledge of the facts will be done in accordance with good practice laid down by law (loi n°2004-806 of 9 August 2004).

You are free to take part or not in a clinical trial about your illness, and a refusal on your part will not make any difference to your care.

- Epidemiological or observational studies in the form of observatories to enable a better understanding of factors affecting the illness, their frequency, their characteristics, their geographical spread or their link with certain environmental risks, or the different ways the illness is treated.
- Therapeutic protocols which assess the effectiveness and patient tolerance of new medicines or new combinations of known drugs, to determine whether a hoped for improvement in earlier studies on a small number of patients is confirmed with a large number of patients. These trials are conducted simultaneously acroiss several teaching hospitals in France or other countries.

The law of 9 August 2004 formalises the practice of biomedical trials, and your participation may only be on a voluntary basis once you have been fully informed by your doctor and you consent, or non-refusal, has been obtained in writing.

Why take part in clinical research ?

To improve our knowledge of the illness and its treatments. Treatments referred to as "standard" which you are offered have all been validated as treatments of choice as a result of prior clinical trials. However, despite progress in medicine, it is important not to be satisfied with current results, but to take steps towards constant improvement in terms of length and quality of life and of progress in our knowledge.

In a department giving treatment, research can take on a number of aspects, of which the main ones are listed below.

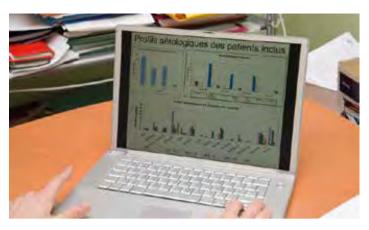
You may be invited to take part in:



 For any questions about a trial, you can contact the team at l'Unité de Recherche Clinique d'Hématologie (URC-H). (Tél. : 05 55 05 66 42).

Dr MP. Gourin, doctor in charge of the URC-H et Chantal Tisseuil , Clinical Research Nurse.

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Recording and Analysis of data about your illness, your treatment and its follow-up

Data about you will be recorded in anonymous form in the data bases of the regional clinical research unit as per the good practice of the *Commission Nationale Informatique et Libertés (CNIL)*⁶. Departments in the CHU have an IT system to facilitate the management of patient notes and if need be, the generation of statistics for internal use. Information collected at your consultation will be recorded on the database unless you specifically object. The information is available only to the medical team looking after you, and administrative data is available only to the accounts department for billing purposes.

Information about biological samples for scientific purposes

Left overs from samples (blood, bone marrow, lymph nodes or other tissue that your diagnosis was based on) may be used in the framework of research into you illness. Results of analyses carried out on these samples for scientific purposes remain strictly confidential and anonymous. You are free to refuse to allow the use of samples for research purposes, without any effect on your care, but if you do, we ask you to fill in, date and sign a refusal form.

What are your rights ?

Access to your medical notes

By simply asking the secretary, it is possible for you to receive minutes of your consultations directly. The majority of doctors dictate consultation minutes in your presence and *a duplicate can be addressed to you automatically,* if you wish.

We would advise you to keep them carefully and take them with you if you go on holiday or away from the region. They may be useful for you in getting a second opinion if you wish to do so.

In addition, *direct access to you medical notes* is now possible since the loi n°2002-303 of 4 March 2002. For this, all you have to do is send your request to the head of the establishment, stating the clinical department and the doctor treating you, and for you to pay for the photocoying. Any doctor nominated by you can also have full knowledge of your medical notes.



Person of confidence (personne de confiance)

If you wish to designate a person of confidence you must do so in writing. One such person can be designated at any one time. It might be a member of your family, someone close to you, or your GP, but the person must also sign the designation. The person you choose may at your request: accompany you on your visits to hospital, be present at medical appointments in order to help you make decisions. The person will not receive any information you judge to be confidential. The role of the person of confidence does not go further than that; she does not take decisions in your place, it is you who decide with the doctor looking

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after you. In the event you are no longer able to express your wishes yourself, the person of confidence will be consulted by the hospital team about the treatment you will be led to receive. The person's opinion will rule in all but medical questions, acting as you spokesperson and will be called upon to indicate what you would have preferred and not his or her own thoughts about the treatment is being suggested.

Advance Directives

However serious or evolving your illness is, advance directives enable you to make known your wishes about the proportionality of your treatment, your values and your end of life wishes, as a result of successive legislation about patients and people nearing the end of their life. As it is not easy to think about the end of one's life, or even to envisage the day when you will not be in a position to express your wishes; the law offers an opportunity to think about it in advance.

Trying to talk about it with those close to you, when you are feeling well, is the best way to make your wishes known. Advance Directives are revocable at any time and they are valid without time limit. The doctor has to respect them when taking any decision on investigation, surgery or treatment for you, except in case of life-threatening arising during the time necessary for a complete assessment of the situation, and when they appear manifestly inappropriate or not in keeping with the medical situation. If a doctor decides not to apply the advance directives, he is required to take that decision in consultation with other doctors, provide reasons for his choice and inform the person of confidence, the members of the family and those close to the patient.

A sample form can be made available to you íf you wish

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	Formulais	e de recueil des directi	ves anticipees	
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Your representatives

A Patients Committee created in October 2008 is taking part in the move to continually improve the quality of the care for patients with blood disorders in Limousin. If you have observations or suggestions to make, do not hesitate to share them via the coordinator,

Sophie TRARIEUX-SIGNOL.

(05 55 05 88 64 - comitepatientregionalhematologie@chu-limoges.fr)



Patient associations

You can contact them to share your experiences or to keep informed of advances in your illness and to meet the dynamic regional volunteers who give them life. In the waiting rooms of the departments you will find brochure holders with information materials from:



France Lymphome Espoir (FLE) www.francelymphomeespoir.fr Référente Limousin : Mme L. Castanié laurence.castanie@francelymphomeespoir.fr

ecm

Connaître et Combattre les Myélodysplasies (CCM) email : associationccm@yahoo.fr

⁶ CNIL : Commission Nationale Informatique et Liberté, Articles 34, 38 et 40 de la loi n°78-17 du 6 janvier 1978 relative à l'informatique, aux fichiers et aux libertés

af3m 🥍

Association Française des malades atteints de Myélome *Multiple (AF3M),*

www.af3m.org Limousin Representative: M. Alain Baudinet, alain.baudinet@live.fr



Association Française contre l'Amylose Tél. : 04 42 94 90 86

www.amylose.asso.fr

Association de Soutien et d'Information à la Leucémie Lymphoïde Chronique et la maladie de Waldenström (SILLC) www.sillc-asso.org/sillc Limousin Representative: Mme Odile Barbier odilebarbier87@gmail.com



Aide aux malades et Lutte contre la Thrombocytémie Essentielle (ALTE-SMP) tél: 04 78 02 03 52 www.alte-asso.org/fr/index.html



Ligue contre le cancer

Comité 87 : Tél: 05 55 77 20 76 email : cd87@lique-cancer.asso.fr

Comité 23 :

Tél: 05 55 52 44 87 e-mail : cd23@ligue-cancer.net

Comité 19 :

Tél: 05 55 20 20 40 e-mail : cd19@ligue-cancer.net



Cancer Support Haute-Vienne Support for English speakers affected by cancer, HELPLINE: 06 04 43 39 87 e-mail: helpline@cshautevienne.org

Your family and those close to you



At appointments you have with doctors in the department especially the one when you are told of your diagnosis, results of tests or proposals for your treatment, your are advised to have someone close to you, your person of confidence or even a carer accompany you.



This enables you not to be the only person hearing information that can sometimes cause great anxiety, and it is up to those near you to understand and help you as best they can. Doctors can also meet members of the family by appointment made with the secretary.

Medical confidentiality

In principle, this prevents information about your state of health being imparted to a third party without your permission. The health professional will give information orally under these circumstances, but only you or a doctor designated by you can have access to your medical notes.

Support Leave (congés d'accompagnement)

An employee of at least 2 years' standing in a company has a right to this leave when his spouse or PACS partner or parent or child in his care, or near relative, suffers a handicap or particularly serious loss of autonomy. The leave is unpaid and lasts for up to 3 month renewable, but may not exceed a year for the entire career of the employee. More information about support leave, and other sickness or family related benefits can be obtained from the social assistant in the department.

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Notes



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PAO

Contact details for Hospital/Community Liaison

Your haematologist Nom : Adresse :

Tél. :



Nom :	
Adresse :	
Tél. :	
Portable :	



our	community	nurse
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1	Your Physiotherapist
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1	Your	ambula	ance	ser	vice

Nom : Portable :....

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CENTRE DESCRIPTION

Your useful numbers



HEMATO-DS-026A - PAO 01-11

Useful Contact details

CONTACTS

Haute-Vienne

- Clinical Haematology Dept, Limoges CHU
 - Consultation :
 - 05 55 05 66 52
 - Hospitalisation :
 - secretaries 05 55 05 66 42
 - rdv Petscan 05 55 05 66 72
 - reception 05 55 05 67 55

Day hospital:

- secretaries 05 55 05 80 38
- accueil 05 55 05 66 62
- Clinique François Chénieux : 05 55 45 44 44
- Saint Junien Hospital : 05 55 43 50 18
- St Yrieix Hospital: 05 55 75 75 64
- Bellac Hospital: 05 55 47 20 03

CorrèzeBrive Hospital :

- 05 55 92 60 52
- Tulle Hospital : 05 55 29 79 71
- Ussel Hospital : 05 55 96 43 21

Creuse

- Guéret Hospital:
- Hématolim Network 05 55 51 48 84
- Medicine Dept : 05 55 51 87 20
- Day Hospital : 05 55 51 87 18
- Bourganeuf Hospital: 05 55 54 50 31
- Aubusson Hospital: 05 55 51 83 09 50
- La Souterraine Hospital: 05 55 89 59 96

EMERGENCIES

8am to 5pm : 05 55 05 66 42 5pm to 8am : 05 55 05 66 72

Freephone number for the Nurse Clinical Haematology and Cellular therapy Dept



A nurse always present Mondays to Fridays from 8.45 am to 5pm.

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Remerciements

Pour la relecture de ce carnet de liaison, aux membres du Comité de patients d'hématologie, aux Drs L. Remenièras du 3CR-H, M. Touati du Réseau HEMATOLIM, J.B. Fargeas et N. Signol de l'UCOG-Hélim, et aux Drs N. Dmytruk, S. Girault, M.P. Gourin, C. Kennel, A. Penot, P. Turlure et au Pr A. Jaccard.

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