

Department of Clinical Haematology and Cell Therapy



Patient's Brochure



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Department of Clinical Haematology
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Dear Madam, Sir,

Dear Patient,

You have just been hospitalised in the Department of Haematoloy and Cell Therapy for the diagnosis and treatment of a blood-related illness. Its diagnosis, treatment and observation will require a specific appropriate form of care which will be fully explained to you. However it may be worrying or even frightening for you to be told about your illness and the practical details of your treatment by medical and paramedical staff in an organisation that you are not familiar with. That is why we have designed this brochure to provide you with some answers to the questions you are naturally asking. The aims of this brochure are:

- to introduce you to the medical team who are looking after you and the various people who will be able to help you during your course of treatment.
- to show you the various kinds of treatment you will be offered depending on your diagnosis, the stage your illness has reached and how serious it is: outpatients, day hospital, full hospitalisation, the Sterile Unit.
- to explain to you the various types of samples, tests, or therapies common to numerous blood disorders.
- to provide you with information about your rights, and information to give your family and friends.
- to provide you with general information about the functioning of the blood, bone-marrow, ganglions and the additional tests specific to blood disorders. You will also find a glossary of the most commonly used medical terms for your guidance.



You will, of course, also be given further information orally by the Department's doctors, nurses and carers and we were at your complete disposal to answer your questions.

If we have omitted any information that seems necessary to you, we would be grateful if you would inform us of your reservation s and remarks on the form provided at the end of the brochure headed "Your comments on the introductory brochure".

Thanking you for your confidence,

Professor Dominique BORDESSOULE







INFORMATION ABOUT •···· THE TEAM CARING FOR YOU

...... Department of Clinical Haematology and Cell Therapy =........ä

The medical team

You are being, or about to be, looked after by a multidisciplinary medical and paramedical team.

The members of the medical team

Professor Dominique Bordessoule – Head of Department

Professor Arnaud Jaccard – Hospital doctor/University professor

Dr Liliane Réménieras – Hospital doctor

Dr Pascal Turlure – Hospital doctor

Dr Mohamed Touati – Hospital doctor

Dr Stéphane Moreau – Hospital doctor

Dr Marie-Pierre Gourin – Hospital doctor

Dr Stéphane Girault – Hospital doctor

Dr Natacha Dmytruk – Hospital doctor

Dr Julie Abraham – Hospital doctor

Dr Amélie Penot - Hospital doctor





Professor Dominique BORDESSOULE is Head of the Department and her duties are as follows:

- She is in charge of the department in administrative terms.
- She sees outpatients on Monday afternoons.
- She visits patients in full hospitalisation on Tuesday mornings.
- She visits patients in the Sterile Unit on Thursday mornings.
- She examines patients' cases in Multidisciplinary Coordination meetings.
- She sees patients' families every day from 5.30pm by appointment (to be made through her secretary, Mme Isabelle BERTELO Tel: 05 55 05 66 42).
- She teaches at the Faculty of Medicine in the afternoons.
- She carries out clinical research in collaboration with national and international teams into the nature and treatment of blood disorders.

Should you have any difficulty in understanding your illness, your treatment and/or its progression, do not hesitate to ask the Head of Department for further explanations. She is at your disposal to answer any questions you may have.

In the Department of Haematology and Cell Therapy you will be looked after by a medical team and by different doctors according to your type of hospital stay and what is involved in your treatment. Your follow-up outpatients appointments can be with the doctor you saw at the time of your diagnosis. He will be your "médecin référent" – the hospital doctor in overall charge of your case.



Professor Arnaud JACCARD (Hospital doctor/University professor) is in charge of this unit comprising 15 beds. His duties are as follows:



- He sees outpatients on Monday afternoons and Tuesday and Friday mornings.
- He visits patients in the unit three times a week in collaboration with the other members of the medical team.
- He submits patients' cases to the Multidisciplinary Coordination Meetings.
- He sees families by appointment (to be made through his secretary, Mme Sabrina MAURY Tel: 05 55 05 66 51).
- He teaches in the Faculty of Medicine in the afternoons.
- He carries out clinical research into amylosis and lymphoid diseases.
- He is in charge of the National Reference Centre for AL Amyloidosis and other monoclonal immunoglobulin deposits diseases. www.cr.amylose-al.fr







Dr Julie ABRAHAM (Hospital doctor) looks after patients in the full hospitalisation sector. Her duties are as follows:

- She sees outpatients on Wednesday afternoons and Thursday mornings.
 She visits patients daily in this Functional Unit where she also
 - assumes responsibility for trainee doctors.
 - She attends the Multidisciplinary Coordination Meetings on patients' cases.
 - She sees families by appointment (to be made through her secretary, Mme Sabrina MAURY Tel: 05 55 05 66 51).
 - She carries out clinical research into lymphoid diseases and bone-marrow transplants.

Dr Amélie PENOT (Hospital doctor) looks after patients in the full hospitalisation sector. Her duties are as follows:



- She consults in the **departement** on Thusdays.
- She visits patients daily in this Functional Unit where she also assumes responsibility for trainee doctors.
- She sees families by appointment (to be made through her secretaries, Mme Ghislaine ASTIER & Elodie CHAMPION Tel: 05 55 05 80 38).
- She sees outpatients at **Guéret** hospital on Wednesdays.
- She sees families by appointment (to be made through her secretary Mme Marie-line ROQUE and Michele VIOLA in Guéret - Tel: 05 55 51 87 20).
- She attends the Multidisciplinary Coordination Meetings on patients' cases.
- She carries out clinical research into chronic lymphocytic leukaemia and agressive lymphoma.



The Sterile Unit

Dr Pascal TURLURE (Hospital doctor) is in charge of this unit comprising ten beds, four of which are laminar flow beds. His duties are as follows :

- He manages this unit on a day to day basis in administrative terms.
- He sees outpatients on Tuesday mornings and Wednesday afternoons.
- He visits patients three times a week.
- He attends the Multidisciplinary coordination meetings on patients' cases.
- He coordinates the Transplant Committee in collaboration with Mme Laure TARDIEU.
- He sees families by appointment (to be made through his secretary Mme Isabelle DARNEIX Tel: 05 55 05 80 39).
- He is in charge of auto- and allo-transplants.
- He carries out clinical research into acute forms of leukemia and haematogenetic stem-cell transplants.

Dr Stephane GIRAULT (Hospital doctor), working closely with Dr Pascal TURLURE, looks after patients in the Sterile Unit. His duties are as follows:



- He sees outpatients on Monday morning and Wednesday afternoons, he is in charge of haemostasis outpatient cases (for patients with hemorrhagic diseases and thrombosis), and has an outpatient clinic at the Regional Haemophilia Centre at the Mother and Child hospital on Tuesday afternoons.
- He visits patients daily in this Functional Unit where he also assumes responsibility for trainee doctors.
- He cooperates in the follow-up of bone-marrow transplants with Dr Pascal TURLURE.
- He attends Multidisciplinary Coordination Meetings on patients' cases.
- He sees families by appointment (to be made through his secretary, Mme Isabelle DARNEIX Tel: 05 55 05 80 39).
- He teaches at the Faculty of Medicine in the afternoons (blood transfusions).
- He chairs the watchdog committee on blood transfusion and haematological safety and, within the University Hospital as a whole, is responsible for biological safety and deputises for the person responsible for haematological safety.
- He carries out clinical research into thromboembolic and hemorrhagic diseases and blood transfusions.





The Day Hospital

Dr Stephane MOREAU (Hospital doctor) is in charge of palliative-care beds. He works closely with Dr Natalia DMYTRUK and his duties are as follows:



- He manages this unit on a day to day basis in administrative terms, particularly in relation to the terminally ill patients.
 - He sees outpatients all day on Mondays.
- He visits patients daily in collaboration with the other members of the medical team.
- He attends the Multidisciplinary Coordinating Meetings on patients' cases.
- He sees families by appointment (to be made through his secretaries, Mme Ghislaine ASTIER and Mme Elodie CHAMPION – Tel: 05 55 05 80 38).
- He coordinates discussions on ethics on Fridays.
- He carries out clinical research into palliative and ethical issues around the end of life.

Dr Natalia DMYTRUK (Hospital doctor) looks after patients in the day hospital. Her duties are as follows:



- She sees outpatients on Tuesday afternoons and Thursday mornings.
- She visits patients daily in this Functional Unit where she assumes responsibility for trainee doctors.
- She attends Multidisciplinary Coordination meetings on patients' cases.
- She sees families by appointment (to be made through her secretaries Mme Ghislaine ASTIER & Elodie CHAMPION – Tel: 05 55 05 80 38).
- She carries out clinical research into lymphoid diseases and nutrition.

Dr Amélie PENOT (Hospital doctor) looks after patients in the day hospital (p. 11)

Within HEMATOLIM, the Limousin Regional Haematology Network

Dr Mohamed TOUATI (Hospital doctor) is in charge of this network and his duties are as follows:



consults in the Department on Monday afternoons and Wednesday mornings.

- He sees outpatients nearer to their home at hospitals in Saint-Junien, Bellac, Tulle and at the Chénieux Clinic in Limoges.
- He attends the Multidisciplinary Coordinating Meetings on patients' cases.
- He sees families by appointment (to be made through his secretary Melle Julie GARESTIER Tel: 05 55 05 60 63).
- He carries out clinical research on Hodgkin lymphoma, Hemoglobinopathy and iron overload.
- He chairs the HEMATOLIM network and organises its work and the regional network ROHLim

Dr Marie-José RAPP (Hospital doctor at USSEL Hospital) is the HEMATOLIM network doctor for the site at Ussel in Corrèze. Her duties are as follows :



- She sees outpatients in the Ussel hospital on Wednesdays every other week from April to October and Tuesdays and Wednesdays once a month from November to March.
- She attends the Multidisciplinary Coordination meetings and presents the cases of patients seen locally throughout the HEMATOLIM network and cases from doctors at Ussel Hospital.
- She takes part in the work of the HEMATOLIM network.



Regional Haematology Coordination Centre [3CR-H]

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Dr Liliane RÉMÉNIÉRAS (Hospital doctor) is in charge of the 3CR-H (p. 55):



- She chairs Multidisciplinary Coordination Meetings on patients' cases.
- Is In charge of the link between the city and the hospital in collaboration with the paramédical team.
- She provides a contact phone line for General Practitioners in the region: Freephone 0 800 88 15 97.
- She sees outpatients on Monday and Wednesday mornings.
- She sees families by appointment (to be made through her secretaries, Mme Agnès DUPUY Tel: 05 55 05 89 75).
- She carries out clinical research within the Department.

Haematology Clinical Research Unit

Dr Marie-Pierre GOURIN (Hospital doctor) is in charge of this unit. Her duties are as follows:



- She sees outpatients on Tuesday and Wednesday mornings.
- She attends Multidisciplinary Coordination meetings on patients' cases.
- She sees families by appointment (to be made through her secretary Mme Isabelle BERTELO Tel: 05 55 05 66 42).
- She is in charge of the Clinical Research Unit and coordinates the various clinical research projects at the Hospital, working closely with the clinical research nurse and associated staff.
- She carries out research into myelodisplasia.

While you are seeing the doctor,

It is possible that for psychological reasons, or as a result of your medication your illness may lead to problems in your intimate relationship. There are solutions. Do not hesitate to talk about them to your specialist doctor, who will point you in the direction of a sex therapist colleague.



As in all teaching hospitals you will also be led to meet **house doctors and medical students** who will come to ask you questions about your illness in order to collect data to do with your medical history. These people are young doctors in training. Medicine is a traditional trade that is not just learnt

by reading books, but also by really working alongside older more experienced practitioners. If you do not wish them to be present, simply ask the person in charge of the department you are receiving treatment in. Otherwise, we are grateful to you for cooperating fully with them – They will be your future doctors!

You should not forget **your own GP**, who is the pivot of your treatment and will see you through your therapy. He works in collaboration with the specialist you are referred to and he or she is the essential link with regard to your treatment when you return home. Communication between the GP and the haematologist is usually done through letters from the hospital. You may have

a copy of these if you wish, by simply asking. Wherever possible, letters from your meetings with the doctors are dictated in your presence. Should any complication or emergency arise, the Department's stand-by number is available to help them with your treatment. It is your GP who looks after the administrative procedures for obtaining 100% reimbursement to which a diagnosis of malignant blood disorder entitles you. Bear in mind that he or she should be the first person you turn to concerning your illness and the best person to advise you on treatment – with the guidance of any specialist opinion that are necessary.









Health Executives

Pascale DORE, As senior health executive her role is to coordinate and manage teams of health professionals by working closely with the Head of Department. Her duties include supervising standards of treatment and nursing. She is in charge of the application for European accreditation (JACIE) in which she is closely involved. Should any problem arise, she is at your disposal: do not hesitate to get in touch with her to find a solution (Tel: 05 55 05 66 46).



Nathalie DUBOSC-MARCHENAY, is the executive in charge of the Day hospital. She coordinates the JACIE European accreditation procedures with regard to blood transfusions. Do not hesitate to get in touch with her about any non-medical problem which might arise while you are in hospital (Tel : 05 55 05 66 69).

A second Heath Executive works in the full hospitalisation section and in the sterile unit. You will meet her during her daily visits with the medical team and her weekly visits with the Head of Department. She coordinates the JACIE European accreditation procedures to do with hygiene. Do not hesitate to get in touch with her about any non-medical problem which might arise while you are in hospital (Tel : 05 55 05 66 75). Currently, Jocelyne PREUX-BOURDELAS is holding this position.

Health executives are there to listen to what you have to say about any problem with regard to planning, organisation and standards of treatment.

Nurse specialized in hemato-geriatric assessment

Diane TILMANT-TATISCHEFF, holds the National Diploma in geriatry :

She will carry out a nurse geriatric assessment, its follow-up, teach nurses of the Limousin and coordinate this mission with other hospitals members of the HEMATOLIM network and home care nurses.

This short geriatric assessment standarized allows to evaluate geriatric risks of elderly patients suffering from malignant haemopathy and to adapt treatments.





Nurse present when you are told of your diagnosis

Corinne BOURDEIX



- Her job is to be with you when the news of your diagnosis is broken to you, by being with you, whenever this is possible, at the appointment at which you are told of your diagnosis. She will, as necessary explain and rephrase the medical explanations about the illness and its treatment, and will show you round the department. She will hand you the patient's manual, the individual treatment plan, and will give you details of the help that may be necessary to enable you to cope with your illness better. She will introduce you to the psychologist, the social worker and if necessary the dietician.
- She will help you fill in the papers required for your course of treatment. She will list the allergies you have and family members who you wish to allow to be told of your diagnosis. She will prompt you to nominate a person of trust and will as required take note of any living will you may wish to make.
- She will draw up for you a list of addresses of any resources, whether for directly care-related or not, or medical or not, which might forge links between your home and the hospital that can be around you to help you in your fight with your illness. (Tel:05 55 05 66 62).

Educational health nurse

Catherine GRANET, holds the National Diploma in health education. Her duties are as follows :



- Reappraising your grasp of the knowledge that is useful in understanding your illness, its treatments and their side effects, and answering any new questions you may have.
- If necessary telling you of any precautions you need to take at home and advising you about everyday life in the light of your habits, being with you from the first moment you leave hospital.
- After you have left, she will keep in touch through personal calls to you at home, contacting your GP, nurses and the pharmacy of your choice if you wish her to.
 - Thanks to funding from the Fund for the Coordination and Quality of Hospital Treatment, the haematology department has set up for your disposal a help-line with a free-phone number. Once you get back home, feel free to use it for advice about everyday life, side-effects of your treatment or any other question related to your illness. (Tel : 0 800 54 32 20).

Nurse in charge of transplant coordination

Laure TARDIEU's duties comprise :



- Assisting you during your appointment with the transplant doctor when you are offered a stem-cell transplant (auto- or allo-transplant).
- Coordinating your transplant with transplant doctors, doctors from the French Blood Transfusion Institute (Etablissement Français du Sang), the highly specialised HLA laboratory, and the Haematology laboratory.
- Attending the Multidisciplinary Coordination Meetings on transplants.
- Explaining to you the different stages and organising the timetable for your transplant, and contacting you in case of any changes to this timetable to keep you informed.
- Do not hesitate to ask her about any practical details that you need to know. (Tel : 05 55 05 80 39).

Clinical research Nurse -

Chantal TISSEUIL, holds the French Inter-university Diploma in the training of Clinical Research Assistants (DIU-FARC). Her duties comprise :



- Meeting you if your specialist offers you treatment in the framework of a clinical research project leading to advancement of knowledge about your illness or its treatment.
- Chantal is at your disposal to provide you with additional information to complement what your doctor has told you, to ensure that the consent she obtains from you is given in full understanding of what is involved, and provide you with a timetable of your blood tests and or treatment.
- She will make it her business if needed to send the blood samples to laboratories which are highly specialised in your illness and to collect anonymised data from your medical notes with a view to studying them with those of other patients with a similar illness at a regional, national and international level.
 - Do not hesitate to ask her for any practical details you might feel necessary. Dial the switchboard on *05 55 05 55 55* then ask for 49704 or 51653 line.



Nurse in charge of coordinating blood transfusions in the Day Hospital •

Sylive REY's duties comprise :



- Giving you your individual blood transfusion schedule drawn up according to your requirements by your specialist. This schedule will be subject to regular reappraisal with your haematologist to bring it closer into line with your illness and your tolerance of anaemia.
- Before your first transfusion the care team doctor or nurse will want to be sure that you have a good understanding of the information about blood transfusions that you will find on page 50.
- Blood transfusions can be organised at the hospitals making up the HEMATOLIM network, providing the same level of quality as near as possible to your home.
- Do not hesitate to get in touch with Sylvie about any difficulties you may encounter. (Tel : 05 55 05 66 62).

Nurse in charge of coordinating treatment between the hospital and localities

Katia AUBERT's duties entail :



- Helping to arrange your return home and remaining at your disposal for any difficulties you may encounter in coordinating your treatment at home and your everyday life after leaving hospital, to avoid unnecessary hospital readmissions and to facilitate keeping you at home.
- Liaising between the hospitalisation department in any establishment in the region where you are receiving treatment and the support teams providing treatment and assistance at home.
- Vou may ask Katia for advice about any difficulty you have in organising treatment and assistance at home (Tel : 05 55 05 88 22 or 06 47 74 88 47).
- Katia's task is at a regional level and is carried out in partnership with the HEMATOLIM network, The Regional Health Agency (Agence Régionale de Santé) and the Cancer League (Ligue contre le Cancer).

The hospital does not stop there...

Psychologists

Estelle RAMPNOUX and Lucile MAUCOURANT



Learning that you have a serious illness is certainly a frightening experience and often reawakens longer standing issues. The whole care team is aware of the psychological difficulties that being told of the diagnosis causes every patient but also those near and dear to him or her.

Estelle and Lucile will make themselves available to you from the moment you arrive in the department. You can meet them while you are in hospital, in the day hospital or just when you are attending outpatients.

Do not hesitate to contact them when you encounter difficult times for you and your family. (Tel : 05 55 05 66 72)

What's more, if you or someone close to you want to consult a psychologist near you, you can take advantage

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of up to six free appointments, taken in hand by the network of independent psychologists within HEMATOLIM, in order to facilitate your return home or to help you cope better during or following your illness. (Tel : 05 55 05 60 63).



Physiotherapist -

The physiotherapists may be called in to help in your treatment at the request of the medical team.

His duties range from helping patients to get back on their feet in order to go home (walking, muscular tone) to respiratory therapy in the case of a lung infection or massages to provide comfort, reassurance and well-being if your condition has worsened.

Physiotherapy sessions are mainly held in the afternoons. Do not hesitate to ask for it to be prescribed for you.





Other sides to the hospital



Relaxation therapist

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Michèle ZYGAR

Relaxation with an experienced therapist may help you to recover your energy and bring you a feeling of well-being during the difficult periods in your illness. Michèle will introduce you to relaxation techniques while you are in hospital and will train you to use them on your own. She is in the department on Monday from 10am to 3.30pm, on Tuesday afternoons, Wednesdays and and Friday from 10am to 3.30pm. Do not hesitate to call her if you wish to take advantage of these relaxation techniques to improve your well-being, through the department's nurses or psychologists. (Tel : 05 55 05 66 62).

Beautician



Séverine AUPETIT

Relaxing body-care with a beautician trained in patient care may help you to keep or regain your personal image and bring you a feeling of well-being. Séverine may suggest relaxing body- and face-massages, cares of hands and feet – carried out with due regard for the precautions against asepsis that are required because your immune system is being suppressed. She gives advices for skin and nails care during treatment.

She is in the department everyday except Wednesday.

Do not hesitate to call the nurses if you feel she could help you ; (Tel : 05 55 05 66 62).







Sophie MONZAT

Diet is one of the key factors in combating illness, but unfortunately chemotherapy, the many types of medication and confinement to bed often do nothing to whet your appetite. Regular visits by a dietician will help you to work out meals that are to your taste while complying with the Haematology department's statements of hygiene. Some foods must be avoided during your illness and while you are in the Sterile Unit. Information and advice will be given by Sophie and the medical team.

The medical team are particularly vigilant about malnutrition as it can easily lead to complications. You may be advised to go on a specific diet, possibly based on :

- A regularly supervised diet.
 Nutritional supplements to
 - Nutritional supplements to your diet to be taken orally.

While you are in hospital you may be offered intravenous feeding or feeding through a naso-gastric catheter. The medical and paramedical team will be there for you if the need arises to give you more information. Dial the switchboard on *05 55 05 55 55* then ask for 54857 or 49835 line.

Social worker

The onset of a blood disease often entails reorganising your working and social life over a fairly long period. As soon as you have been informed of your illness or you arrive in the department, a social worker will come and take stock with you of any social, material or professional assistance that you illness and its treatment may lead to – for example, possible problems with looking after your children, or a person dependent on you or even your pets or farm animals.

Working in collaboration with the medical team, she helps to arrange your return home and will assist you to find the most suitable solutions: required equipment, or alterations to be carried out to your home, in cooperation with your insurance company.

Should the need arise she will liaise with the Cancer League (Ligue contre le Cancer) when patients encounter difficulties in obtaining assistance. Should the situation change while you are under treatment, do not hesitate to call on her to adjust the assistance package to be put in place as you go along. (Tel: 05 55 05 60 11).

You can call on these different care staff by asking a member of the department staff.





The paramedical team passing on their knowledge



The whole team is at your disposal and that of your local doctors and nurses to keep them informed and to provide them with training when necessary.

The hemato-geriatry within the department

Hemato-geriatric assessment is a multidimensional, interdisciplinary diagnostic process to determine the medical, psychological, and functional capabilities of patients over 70 years old with malignant haemopathy in order to develop a coordinated and integrated plan for treatment and long-term follow-up.

While integrating standard medical diagnostic evaluation, hemato-geriatric assessment emphasizes quality of life and functional status, prognosis.

Consequently, you may meet Diane (p.18), a nurse specialized in geriatrics for a test of thirty minutes to evaluate your health status.

It may also be suggested to you a medical consultation by a physician specializing in hemato-geriatry. Three doctors provide consultations. These doctors are: M.A. PICAT, N. SIGNOL, J.B. FARGEAS.







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 Bepartment of Clinical Haematology
 Information on the various

 and Cell Therapy
 sub-department units within the department

The start of your treatment

Dealing with the formalities

To avoid wasting time, be sure to go to the "Consultations Externes" reception desk on the ground floor. [Take a numbered ticket from the dispenser and wait for the number to appear on the screen with the number of the desk to go to to "check in".] An outpatients form will be filled out in your name. You will need to produce your identity card or passport, your green health-card ("Carte Vitale") and the attestation that came with it and the attestation from your top-up insurer ("Mutuelle").

On your first visit to the department certain formalities have to be carried out however long your stay:

You will be welcomed by a nurse or by the health executive, who will explain your treatment schedule in the day hospital or in the full hospitalisation and give you forms to fill in to enable us to know you better:

A blue coloured form on which to list the members of your family and friends that you authorise to be told news about you and your diagnosis. You may if you wish inform the team about the person you have chose as your "personne de confiance" a person you trust to speak for you if the need arises, and convey your living will.

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A form on which to list any allergies you may have and adverse reactions to supplementary tests you are offered.

You will only be asked once for the information that you provide on your first visit which will be archived in your notes. The whole medical and nursing team will have access to this information, which enables it to be shared and to enhance the quality of your treatment. Do not hesitate to ask us to update it should a change in circumstances arise.

Come to the hospital with any documents that will be useful in your treatment :

- A list of treatments you have received or prescriptions you have been given by your regular GP.
- Any X-rays or biological tests carried out prior to your coming into hospital.
- Your blood-group card.
- The patient's manual that will have been given to you at the moment of diagnosis, along with your initial treatment schedule. If you haven't received these, it will be given to you by the senior doctor or a member of the medical staff at the very beginning of your treatment.

When you come into the hospital either for treatment or to outpatients, be sure to bring this manual with you, as it contains the important elements of your diagnosis (results of biopsies or other information) and of your follow-up (such as blood counts or protein electrophoresis tests) as well as duplicates of your prescriptions.



in the department of Clinical Haematology and Cell Therapy

For follow-up treatment, bring the following with you:

Your list of questions.

- A summary of any important events that have taken place since your previous visit to the department or outpatients appointment.
- Any change in your personal details, address or telephone number.

Communication with the outside world

- Telephone: As soon as you know your room number you can ask the hospital reception to activate your telephone, or you can dial 10 as soon as you have settled into your room. You may also use you mobile phone.
- Mail: It is more convenient for the hospital to have your mail delivered to the department. A member of the care team will give you details of the address to use.
- Television is free of charge in the Haematology department thanks to the generosity of associations, charity groups and of donations from patients or their families.
- Flowers and plants are a source of contamination in hospitals, and as a consequence they are not recommended, especially in sterile units. Ask for advice from the care team.

Planning your return home starts as soon as you arrive in the department.

- With the doctors and nurses: You will be visited by Catherine GRANET, the
 - health education nurse, who will give you your prescriptions, you personal treatment plan, with details of your next appointments. She will also check that your coordination form (between the hospital and your local medical carers) has been properly filled in. If need be, she will help your local nurse to get training in the care you need at home.
- The social worker may arrange a period of convalescence near your home or a reorganisation of your living space at home. This kind of organisation often takes time, which is why the people dealing with follow-up need to be warned as early as possible.

Organising your return home as well as possible

When you leave our hospital you will not be left to fend for yourself. We will stay at your side.

Depending on what is medically prescribed for you, your own GP may be able to continue your treatment in collaboration with specialist follow-up either :

- In the day hospital,
- In a centre specialising in follow-up treatment, in a convalescence centre or a medical care home,
- In home-based hospital care (HAD),
 - Through the HEMATOLIM network.





Outpatients

Our Outpatients are seen on the 8th floor, lift B. The clinic is shared with other departments.

A carer will greet you as soon as you arrive and will answer any questions. A team made up of three nurses deals with samples and tests after you see the specialist and organises your next appointment.

Should you be unable to keep your appointment, please let the department know at least 24 hours beforehand so that it can be taken by someone else. (Tel : 05 55 05 66 52)

Haematology outpatients are held every day as follows :

- Monday mornings : Dr L Réménieras, Dr S Moreau, Dr S Girault.
- Monday afternoons : Prof D Bordessoule, Prof A Jaccard, Dr M. Touati, Dr S Moreau.
- Tuesday mornings : Prof A Jaccard, Dr P Turlure, Dr M.P Gourin, Dr A. Penot.
- Tuesday afternoons : Dr N. Dmytruk, Dr A. Penot.
- Wednesday mornings : Dr L Réménieras, Dr M Touati, Dr, M.P. Gourin.
- Wednesday afternoons : Dr P Turlure, Dr S Girault, Dr J. Abraham.
- Thursday mornings : Dr N Dmytruk, Dr J. Abraham.
- Friday mornings : Prof A Jaccard.

Outside these time slots emergency consultations are carried out by the doctor on call, at the request of a family doctor (Tel : 05 55 05 66 42 from 8am to 5pm ; and 05 55 05 67 55 after 5pm.)







The Day Hospital (HDJ) -

This Unit is located on the 8th floor, in the right hand corridor of A-wing; access is by Lift B. It is open from 8am to 6pm from Mondays to Fridays, and is closed at night and during the weekends. Outside these opening hours, continuity of care is provided through an emergency number: 05 55 05 67 55.



The team of doctors and nurses will do everything they can to ensure that your visit goes as smoothly as possible.

■ Your appointments for chemotherapy sessions and for blood transfusions or your individual treatment schedule will be arranged in advance.

■ As soon as you arrive, the nurse in charge of you will give you the schedule for the day in hospital, with the times for tests and appointment.

■ The timetable in your appointment letter has been carefully constructed to take account of the different tests and treatments you are to undergo, and we ask you to be on time and follow the schedule.

As far as possible the same nurse and the same doctor will look after you each time you come.

Lunch will be provided for you and if you wish, a light meal in the afternoon before you leave.

■ You should not leave the department without informing the nurse looking after you.

If you have regular follow-up in the Day Hospital, **the necessary blood tests** may be carried out in your local laboratory. We would be grateful if you would have them done 48 hours in advance and bring the results with you to the Day Hospital so that we do not have to do them again.

It is therefore very important, to enable you to have available these results which are so useful when deciding on your treatment, that you remember to have these blood tests done in good time; i.e. not having them done the day before you come to the Day Hospital, as there would not be enough time to have the results back.

If it is not an emergency, avoid having your tests the day before holidays and the weekend, as the Day Hospital is closed and you may have to have recourse to the emergency services.

On case of any problems about your appointments, please let the Day Hospital reception or the health staff. Their numbers are 05 55 05 66 62 or 05 55 05 66 69.







Full-time hospital



The full-time hospital is located on the sixth floor of A-wing; access is by lift B.

The day and the precise time of your appointment will depend on the tasks and treatment that have been scheduled. We may, due to emergency cases, have to postpone an appointment. We apologise for this in advance: ours is the only Haematology Department in the Limousine Region.



Hospitalisation in the sterile unit



To be effective, the treatment of your illness may require intensive chemotherapy which will lead to a period of temporary aplasia i.e. a decrease in all blood cells (red cells, white cells, platelets).Your bone-marrow will function again normally, but not for a few weeks.

This phase, called "aplasia", is when infectious complications may arise as your white cells are no longer there to protect you from germs and viral infections.

To get through this period of aplasia as well as possible, you will spend it in a room in a special isolated unit.

Consequently, a number of rules and procedures are absolutely necessary. The following information will help you to prepare for your arrival in this unit. We advise you to read it carefully.







This unit is located on the sixth floor in the left-hand part of B-wing; access is by lift B. When you arrive a nurse will greet you.

Ring the bell and a nurse or carer will come to meet you and will give you full details about your stay there. This is a specific unit with specialist equipment : controlled airfiltration and a protective "curtain". Treatment in one of these rooms involves aseptic precautions.

The details of your stay in the sterile unit will be explained to you by a member of the care team or by Laure TARDIEU, the nurse in charge of transplant coordination.

When you enter the laminar flow area, you must put on overshoes, a mask and a protective overall. Before leaving the room, you must wash you hands very thoroughly using antiseptic soap, dry them carefully and then apply hydrated surgical spirit.



The audiovisual equipment in the rooms has been provided thanks to generous donors and is free of charge.

The unit comprises 10 single rooms, all with the following:

- Telephone,
- Television and VCR (free of charge),
- Radio and CD player,
- A clock.






Rules that must be followed

Your clothing

Special precautions are to be taken regarding your linen: It has to be changed every day during the period of aplasia (only if you are staying in the laminar flow area). Linen is provided by the hospital, but you may bring your own clothes. They will be treated like hospital linen and sterilised. Consequently if you wish to use them you should arrange:

- To ask your family to bring in clean linen regularly, uniquely made of pure cotton so that it will withstand being sterilised (night-dresses, pyjamas, underwear, tee shirts, underpants, turbans).
- To bring them the day you arrive in the sterile unit so they will be available 24 hours later (time required for sterilization). The hospital will lend you clothes during this period.
- To bring with you light-weight plastic swimming shoes for us to decontaminate when you arrive. Slippers are not allowed in the sterile unit.



Your toiletries

Each room has a washbasin with purified water and antiseptic soap. You are requested to bring the following:

- A new comb;
- A very clean electric razor;
- A brand-new face-mister;
- Individually wrapped paper handkerchiefs;
- A cardboard nail file;
- A brand-new "soft" toothbrush;
- Liquid soap are allowed.
- Tablets of soap are not allowed.

·····= Information on the various sub-department units within the departmen Department of Clinical Haematology and Cell Therapy

Your diet in hospital

With a view to limiting the risks of infection from certain foods, the Haematology team (doctors, nurses, carers and a dietician) has drawn up recommendations about foods that are permitted or to be avoided, (those which could be dangerous when your immune system is inhibited) and that you may or may not eat during your stay in the protective sterile unit.





Kinds of food	To be recommended	
Breakfast	 Bread and breakfast goods provided by the hospital, individually wrapped biscottes, individual portions of butter. Wrapped portions or cubes of sugar, provided they are not opened in your room (causing dust to be released). Jelly, honey and jam in individually wrapped portions. Cereals in individual packets with no dried fruit in. 	
Starters	Hors d'oeuvre mad with peeled or tinned vegetables. Soup in cartons or dehydrated soup mad up with boiling water.	
Main courses	Tinned food (lentils, cassoulet, sauerkraut) and other vacuum-packed ready- cooked meals	
Cheese and milk products	Processed cheese ("Vache-qui-rit) in individually-wrapped portions or in sealed wrapping. Tinned plain milk products and UHT milk products	
Desserts	Peeled fruit (bananas, oranges, apples), fruit in syrup and stewed fruit in industrially produced containers, individually wrapped biscuits and sponge cakes.	
Beverages	Plain and flavoured UHT milk in cartons, UHT fruit juices and chocolate flavoured milk in cartons, still or sparkling mineral or spring water in bottles of not more than 50cl, light, still or sparkling soft drinks in 33cl cans or bottles, freeze-dried coffee made with boiling water, tea and herbal tea (freeze-dried or in individual sachets).	
Miscellaneous	Mustard, ketchup, mayonnaise and salad dressing in individually-wrapped portions.	



Cans and bottles should be consumed within 24 hours, their contents must be poured into a glass.

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Your diet must continue to be as varied and balanced as possible, either following the hospital's own menu or with a replacement foods available in the hospital or provided by your family and friends.

We would be grateful if you would get in touch with a carer and/or with Sophie, the department's dietician.



To be avoided

Cooked meats, sausage etc, raw vegetables, vegetables that cannot be peeled, seafood.

Red meat, raw fish, even wrapped in individual sachets, shellfish, all kinds of frozen food, howecooked dishes (the coold chain must be observed by law), caterers' ready-cooked dishes.

Cheese that is not sold pre-packed, cheese in individually wrapped portions, cheese with any kind of mould (roquefort, bleu de Bresse, camembert), cheese made with untreated milk ("lait cru"), milk products that are not UHT.

Grapefruit, peaches, kiwis, and fruit that cannot be peeled.

Cakes, biscuits and confectionery that is not individually wrapped and/or contains dried fruit, confectionery in bars or that contain hazel-nuts or other kinds of dried fruit. Cakes with dried fruit in

Ice-cream and sorbet (water-ice) that is not in individually wrapped portions.

Yoghurts, whether they are plain or flavoured, fromage blanc (white cheese), petits suisses, and other milk products that are not UHT or tinned.

Milk products containing dried fruits in the raisin family.

Tea and herbal teas sold unpackaged in individual sachets, all beverages made with squash, pasteurised milk, chocolate flavoured drink made up from powders.

Pepper and other spices added after cooking, savoury biscuits.

For tinned food, use only tins that do not require a tin-opener.

Department of Clinical Haematology
 Bepartment units within the various
 and Cell Therapy

Your diet at home

A few precautions have to be taken :

1/Buy wisely :

- Never exceed the use by date (date limite de consommation, DLC) on wrapped fresh products.
- Beware of eggs with soiled shells.
- Packaging mist always be intact.
- Give preference to class I fruit and vegetables.
- Beware of blown, dented or rusty tins.
- Consume meat and fish on day of purchase.
- Do not buy cooked dishes at the delicatessen counter or ready-cooked pastries.
- There are no limits on frozen foods as long as they are well-cooked.

1/ Choose your food carefully :

- Cooked meats and sausages etc sold loose are not allowed. Only tinned or vacuumpacked meat products are allowed.
- Do not buy fermented cheeses and cheeses sold loose or milk products served by the ladle, but only those packed in the factory and wrapped in individual portions.
- Raw and undercooked eggs (i.e. soft-boiled or fried eggs) are not recommended.

A cool bag must always be useful for carrying fresh produce. Bacteria thrive at room temperature and develop as soon as refrigerated or frozen food starts to warm up.







3/ Keeping food safe :

- Respect the temperatures at which food should be stored.
- Wrap foods separately to avoid unnecessary contact.
- Ideally the temperature in a refrigerator should not rise above 3°C. Check for greater safety !
- Only four star freezers (****) which run at -18°C keep frozen foods properly.
- Food that has been home-frozen or home-bottled is not recommended.
- Never re-freeze food that has previously been defrosted.
- Defrost your food wisely. Give preference to food that can be cooked from frozen, or, if necessary defrost it in your refrigerator. Avoid defrosting at room temperature.
- Once the meal is over, throw away any left-overs.

4/ Hygiene in the kitchen :

- To avoid any infection, perfect food hygiene is essential.
- Wash and disinfect the worktops with a solution of bleach (eau de Javel) 20ml to a litre of water.
- Be sure to clean, disinfect and defrost your refrigerator regularly.
- Do not allow your pets to come and go near food or the worktop.
- Wash your hands carefully with soap and hot water or hydrated surgical spirit solutions as often as required, especially before and after cooking anything.
- While you are preparing food, wash your utensils and worktop between the different stages.
- Wash the crockery, cutlery and utensils very carefully and store them in a clean closed cupboard.
- Use only stainless steel tin-openers and scissors etc., and wash them after every use.
- Clean the tops of tins carefully before opening them.

5/Preparing food :

- As far as possible do not prepare your food in advance: leave everything to the last moment and serve the food rapidly "from the pan to the plate" to minimise the number of time it is handled.
- Let food simmer properly: keep it on the stove until you are ready to eat.
- If you want a second helping, keep the pan hot on the stove.

Watch your weight

If you lose weight, split the days into 4 or 5 mealtimes. It is important to keep your weight stable. If you are unable to keep it stable, do not hesitate to get in touch with Sophie MONZAT, the dietician, for advice about your diet.



..... Information on the various

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department units within the departmen

Leisure activities

Some rooms are equipped with laptop computers connected to the internet, or exercise bikes. We also have a library of videos, CDs, CD ROMs, and DVDs that can be lent on demand, subject to availability.

You may bring in your own equipment, but ask staff to "prepare" it before it is brought into the room. Depending on what they are made of, the things you bring into your room have their surfaces decontaminated.

Things you bring in might include:

- Video-cassettes, CD ROMs.
- Canal+ decoder.
- Videogames console.
- Your own laptop computer.
- A mobile phone.

To keep you amused you might also bring in the following:

- Games: a brand-new jigsaw puzzle (not more than 500 pieces), cards, solitaire, scrabble, chess...
- Reading matter (brand-new books or magazines): a TV schedule magazine, magazines printed on shiny paper (not magazines printed on newsprint), paperbacks (3 or 4), comic books, crossword puzzles. Books are sterilised with heat. Please do not bring precious books with you.
- Stationery: ball-point pen, pencil, notepad, sheets of plain paper, telephone number list, post.
- Handicraft materils: painting (watercolours), crochet or tapestry-work (in kit form in their wrapping), knitting (allowed if the ball is pure cotton).
- Photographs in plastic film may be put up. Do not hesitate to add a personal touch to your room.

Avoid bringing in money or jewellery, except your wedding ring.





Disits

Certain rules have to be observed when you enter the department, irrespective of which section of it you are coming to :

- Take precautions to ensure the safety of the relative or friend in hospital you are visiting: It is not desirable for children to visit (but it can be discussed with the doctor), nor anyone suffering from an infectious illness (cold, influenza, sore throat or gastroenteritis) who are likely to infect those around them nor those who are in touch with young children suffering from childhood illnesses etc.
- You should leave the room during treatment and wait in the waiting-room or at the entrance near the lifts. Do not remain standing in the corridor, where you might be in the way of the medical staff and carers moving patients.
- Please also be thoughtful about not tiring other patients by making too much noise.

The rules will vary according to the type of treatment and the hospital sector :

- In the Day Hospital: you may bring someone with you. We ask you not to have more than one person with you as too many people in the room might disturb patients trying to rest.
- In the full-time hospital visiting starts at 1pm, mornings being taken up by treatment and the consultants' rounds.
- In the Sterile Unit: visits are limited to two people per day, with only one person in the room at any given time, but with no limit on the length of the visit. It is important to follow the instructions you will be given by medical team and which you will find on page 37 of this manual.

Should you have any problems with these times, contact the health executives in the department, who can alter the visiting times to meet individual needs.

Accommodation for family and friends

To help your nearest and dearest cope with your being in hospital, they can stay at the Home du Buisson close by the CHU. This is a socially orientated establishment with no medical facilities.

Rue du Buisson, 87170 ISLE (Tel: 05 55 01 54 85)

Prices from €39.70 for a double room and €31.76 for a single.*

Prices may be reduced according to the general Social Security regime or the incomes of those concerned.

PENDANT, AVANT OU APRÈS L'HOSPITALISATION ..

Familles de malades hospitalisés ou patients ne nécessitant pas de soins ou de surveillance médicale, le Home du Buisson vous accueille dans un cadre de vie reposant. Une équipe de professionnels assure un accompagnement personnalisé, prévient l'exclusion des personnes touchées par

cersonnaise, previen rexclusion des personnes rouches par a maladie et se met à disposition des résidents pour un soutien moral ou pour les démarches administratives.

Réservez une chambre

Au Home du Buisson, vous avez la possibilité d'être logé dans une chambre simple ou double, meublée et tout confort : bureau, rangement, salle de bain, WC, TV, WiFI, restauration. Conformément aux accords avec la Caisse régionale d'assurance maladie ou autres régimes conventionnés, le prix de la chambre est dégressif en fonction de vos ressources, sur remise de justificatifs à fournir pour tarif adapté: carte vitale et de mutuelle, pièce d'identité, demier avis d'imposition, bulletin de situation de moins de 6 mois de l'Hôpital.

> Tarifs, petit-déjeuner compris^{*} : Chambre simple : 31,76€ Chambre double : 39,70€

Contact

Home du Buisson 4 rue du Buisson - 87170 ISLE Tél : 05 55 01 54 85 Fax : 05 55 50 05 53

Coordonnées GPS : 45°48'39.32"N / 1°13'57.76"E



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------ Information on the various

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sub-department units within the department





General information •··· concerning your treatment

Whatever the diagnosis or treatment prescribed, management of haematological disorders will probably involve any or all of the following:

- Implanting a catheter tube into a deep vein.
- Transfusions of blood products.
- Recording and analysing the characteristics of your illness, its treatment and its response to treatment, the data collected being held anonymously.
- A number of samples (from blood, bone marrow, lymph nodes or other tissues) exclusively taken in the course of diagnosis or normal treatment, may be kept frozen for the purposes of further research into the disorder that affects you.

If you require any clarifications on information given in this booklet or about your course of treatment do not hesitate to ask any member of the healthcare team.

Central Venous Catheters

Tapping into the central venous system

Fitting a drip directly into a peripheral vein (often in your upper forearm) is suitable only as short-term solution designed to last for a few days. As time goes by, the risks of infection rise and there is a greater chance of the line becoming blocked.

For increased comfort and the safe administration of medication over longer periods, the best solution is to implant a device into a deep vein.

Two main methods currently exist:

Catheters

A fine tube made of a tough, flexible material that is inserted through the skin into a deep vein situated below the collar bone or more rarely into the jugular vein at the base of the neck. The other end of the tube is connected directly to a drip device.











Implantable devices

A catheter inserted into a deep vein runs from there to a small reservoir implanted just under the skin. When required, the reservoir can be attached to a drip or syringe using a specially designed needle. You can choose which side of your body the port is placed.

These devices need to be fitted under either local or general anaesthetic in an operating theatre by staff trained in carrying it out – anaestheist, resuscitator or surgeon. The correct positioning is checked by X-ray during the course of the operation. Before fitting, your blood coagulation time and platelet count will be determined and if necessary you will receive a transfusion of platelets to boost blood levels.

Risks associated with implanting catheters

- Bruising where the catheter enters the skin.
- Accidental puncturing of an artery requiring pressure to stop bleeding.
- If the catheter perforates the outer pleural membrane when being fitted into the vein just under the collar bone, this may provoke collapse of a lung (pneumothorax) as air enters the pleural space. Because this risk is recognised, close monitoring (chest x-rays) of the operation ensures that in the case of such an accident a drainage tube can be rapidly introduced and the lung expanded. The tube normally has to remain in place for a few days, after which it can be removed without the need for anaesthetics.

The operation to implant a catheter or in-dwelling port device is carried out under strict conditions of hygiene to avoid infection of entry sites and underlying tissues. Measures to keep the area aseptic involve thorough washing of the skin with an antiseptic solution carried out several hours before surgery and once again in the operating theatre. Shaving of excess chest hair is sometimes necessary to enable proper disinfection of the skin. If you are allergic to iodine, please let the medical team know as the antiseptic solution contains this substance.

The procedure itself takes place in surgical conditions with the area around the site of the insertion being kept sterile. All those present are in sterile clothing and have sterile gloves. Despite these precautions, there is a small risk of infection occurring at the implantation or insertion site. Nursing staff looking after your dressing will closely examine the area. This care of the wound is generally sufficient using local antiseptics. In a few rare cases this may not be enough to contain an infection and the catheter or implant will have to be removed.

Once in place, the device will be checked regularly to ensure proper functioning throughout your treatment. After two or three years or remission of your illness, your can ask for the implantable port to be removed. Department of Clinical Haematology

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Peripherally Inserted Central Catheters (inserted into a vein in your

arm):

This is a central catheter inserted under local anaesthetic into a peripheral vein in the arm. Starting from the vein in the arm, the catheter is manoeuvered as far as a deep so-called central vein under X-ray control. The catheter is fixed to the skin using an adhesive device called Statlock® that does not require a stitch.

The risks associated with this procedure are those of infection and haemorrhage.

If you wish to take a shower, you will need to cover it with an occlusive dressing to avoid any water reaching it.





Maintenance and care

Dressings must be changed every seven days during the treatment period and the insertion site carefully cleaned and checked for soundness. Check that the catheter is firmly attached to your skin. Also check that the dressing is tightly closed around the catheter where it enters your skin. Any opening is a potential passage way for infections and you should let the nurses know as soon as possible, so that they can redo the dressing.

Despite the best of care, catheters sometimes become blocked. Blood clots can be cleared by injecting a product into the catheter at the hospital but if unsuccessful, the catheter must be removed altogether. You can use the general "green" number 0800 54 32 20 or the department's number 05 55 05 66 62 to arrange for the catheter to be unblocked, and this must be done without delay.

As long as the catheter is not violently handled the risk of it becoming holed or broken is virtually nil. It is strongly advisable not to manipulate the catheter, especially not using any force or pulling at it or to have it manipulated by anyone not trained in looking after catheters.

Showers are allowed only if the dressing is completely waterproof.

Implantable Port Device:

To follow up the healing of the skin around the point of insertion of the port, dressings are changed every 2 days by a nurse until healing is complete (around 10 to 15 days). Once it is healed, the dressing is removed and showers and other forms of care are possible.

Special considerations:

- Neither a catheter nor a implanted port means you should not fastening your safety belt.
- These devices do mean you should not use probiotics (living micro-organisms or yeasts) to protect them.

For the PICC catheter :

This uses specialised techniques and equipment that requires liaison between your own local nurse and those from the hospital department.

Removal of Implanted Devices

Catheters: As soon as it is no longer necessary (or if a blockage or infection occurs), the catheter must be removed. Where a simple catheter is involved, removal is done by simply pulling it free. This commonplace procedure generally does not result in bleeding or bruising and the orifice heals spontaneously within a few days.

Implantable Port Device: The device must be removed when no longer needed (or in the case of a blockage or infection). This must be done surgically under anaesthesia by the surgeon. The opening left in the skin requires one or several stiches, which are taken out after a few days when healing is complete.

Information about Blood Transfusions -

From the official booklet approved by the Blood Transfusion Safety Committee of Limoges Teaching Hospital

If necessary, during your stay in hospital and if required because of your circumstances, you may possibly be given blood products. These can be divided into two main categories:

Labile blood products

Plasma-derived therapeutic products

Labile Blood Products

Red blood cells, platelets or plasma, **prepared**, **distributed** and scrupulously **checked** by the French National Blood Bank from blood given by carefully selected voluntary donors. Such products strictly fulfil all legal requirements with regards to safety and quality.

Despite these precautions there remain risks and side-effects.

- Common reactions include itching skin, shivering and/or fever.
- Mismatched blood groups provoke clinical accidents, but testing before transfusions prevents this.
- Viral or bacterial contamination can occur in extremely rare cases despite the rigorous checks carried out on donors' blood. Our last case of contamination was in 2001.

- The risk of viral contamination continues to shrink, and the residual risk is 1 case in a million for Hepatitis B, 1 case in 12.5 million for Hepatitis C, 1 case in 2,950,000 for IADS and 1 case in 8,300,000 for HTLV (based on 2008 statistics) - The residual risk for bacteriological contamination is case in 180,000 transfusions.

This is why:

If you receive a transfusion, it is recommended that a blood test is carried out a month or two later to check for antibodies that should not be there (those directed against antigens).



Blood derivatives

This category of transfusion products is based on blood plasma given by selected voluntary donors. The products are specially prepared and distributed by pharmaceutical companies and can only be used for therapeutic purposes after stringent testing.

Unlike the labile blood components described above, these plasma-derived products necessarily undergo viral screening and decontamination, in particular to eliminate viruses such as hepatitis C and HIV.

As is the case for all medicinal drugs, health authorities if necessary can advise withdrawal of specific batches of plasma-derived products purely as a precautionary measure whenever they see fit.

Consequently, we recommend you ensure:

- All treatments are fully recorded in your medical notes.
- Your local doctor is informed if you change address.

If you have any questions, do not hesitate to seek further advice from doctors in the hospital or your own local GP.

Are other risks likely to arise?

Some possible cases of transmission of variant CJD (Creutsfeld-Jacob disease) have been reported in the UK. In France no such case has been reported and the residual post-transfusion risk seems currently low; however a theoretical risk or other risks hitherto unknown, cannot be excluded.

Warning! Be sure to keep safely the documentation you are going to be given.

All information about the blood products that have been given to you will be passed over to you when you are discharged from hospital. Keep them safe and show them to your GP. It is to be desired that this treatment is recorded in your medical notes. Be sure to make known any change of address.

The doctors at the Limoges CHU are available to answer any questions you have.



····■ General information concerning your treatm<u>ent</u>

 Department of Clinical Haematology and Cell Therapy







PUTTING THE CANCER PLAN Into practice : Teamwork

Telling you about your diagnosis

There will be various stages to your progress through treatment, which will involve a multidisciplinary approach. The arrangements for telling you about your diagnosis (measure 40 of the Cancer Plan) enable the patient to have individualised support when being told they have a form of cancer. Its objective is for you to learn of your diagnosis in the least painful way possible.

There are three stages to this procedure.

- An appointment when you are told about the diagnosis: This takes place following, or not, your first appointment at the hospital. The doctor informs you about your illness and the different ways of treating it. After this appointment, your case is referred for coordination to a multidisciplinary medical team, so the most appropriate course of treatment for your particular circumstances can be offered to you.
- The appointment when you are told about your treatment: This takes place after a Multidisciplinary coordination meeting (RCP). The doctor offers you a personalised care plan (PPS) which describes the main stages of your treatment and a provisional programme. At this appointment, do not hesitate to ask questions about your illness and its treatment.
- Meetings with nurses: This is a period during which a nurse will provide support and ascertain your requirements. She will suggest appointments with specialist health professionals, such as a social worker, psychologist, dietician, relaxation therapist beautician, physiotherapist according to your needs.

At the end of this process, a nurse will hand you a personal care plan (PPS) where you will find noted your test appointments, the date your case is to be presented to the Multidisciplinary coordination meeting (commonly referred to as RCP). In as much as it is possible, a letter will be sent to your GP in advance of this meeting, advising him of your diagnosis and enabling him to send any additional information.

Note any questions which are worrying you and any information that seems to you to be important to communicate to the care team on the "Communications" pages starting on page 102.



The Regional Haematology Coordination Centre (3CR-H)

The 3CR-H in the Limousin region coordinates the Multidisciplinary coordination meetings (RCP). These are held at the Limoges CHU in the Department of Clinical Haematology and Cell Therapy, on set dates. It is not only haematologists who attend these meetings, but also other specialists, depending on the nature of the Multidisciplinary Coordination Meeting (clinicians, biologists, anatomical pathologists, radiologists, scanner specialists, specialists from the French National Blood-Transfusion Institute, technicians, state registered nurses of general practitioners from the Limousin region as a whole).

The purpose is to choose, on a multidisciplinary basis, the pattern of treatment best suited to the patient.

Multidisciplinary Coordination Meetings (RCPs)

RCPs of the 3CR-H are of the following kinds:

- **RCP Lymphoide** discussing cases of Lymphoma and related illnesses, on Thursdays from 2.30pm to 5.30pm.
- **RCP Myéloïde** to discuss cases of bone-marrow cancer and acute leukaemia, on Fridays at 3pm.
- **RCP Greffe (Transplants)** to discuss auto- and allo-transplants on alternate Thursdays at 8.30am.
- **RCP Greffe interregional** (Bordeaux, Toulouse, Limoges) The first thursday of each month at 8 am by videoconference.
- **RCP Immunopathologie** to discuss cases of myeloma, cytoplastic dyscrasia and chronic lymphoid leukaemia on Thursdays afrom 5.30pm to 6.30pm.
- **RCP AL Amyloidosis -** on Thursday at 6.30pm. National RCP for patients referred



■ RCP Réflexion, support and palliative care on alternate Fridays from 2pm to 3pm – to discuss the pros and cons of all kinds of care and treatment in difficult cases where there is no response to treatment.

to Limoges for second opinion.

------- Department of Clinical Haematology _______ Putting the cancer plan into practice : and Cell Therapy _______

Multidisciplinary Coordination Meetings (RCPs)

The aim of these meetings is to enable all patients suffering from malignant blood disorders to benefit from well thought out multidisciplinary decisions about treatment.

Taken on the basis of a regional frame of reference adapted from national and international ones. These fames of references are regularly updated on the basis of the latest published medical research data.

Every new case diagnosed in the Limousin is presented for discussion in such a meeting by the senior doctor in charge of the patient. Should this doctor be absent, the case may be delegated to one of his colleagues.

Your case will be re-discussed at intermediate and end of treatment appraisals. In the event you don't respond adequately to treatment or you have a relapse, your case will be presented to the RCP again.

The RCP's opinion is based on a request form the doctor fills in giving the necessary data from the various tests carried out to assess your case. The RCP's opinion will be added to the form, completing it, before being distributed as the minutes of the RCP meeting to all the doctors looking after you, and being filed in your medical notes.

The doctor in charge of your case will tell you what the RCP proposes at the appointment when you are told of the treatment (see page 54). He remains in overall charge of your treatment. If he does not feel that the RCP's suggested treatment, based on the data he collected for them, is appropriate, or if you yourself do not wish to accept it, you will be able to make another choice in discussion with him and having looked at the benefits and risks.

In circumstances when treatment needs to be started as soon as possible, discussion of your case by the RCP may take place after treatment has been initiated. The case will then not be registered until after treatment has been put in place, but it will still be subject to a real discussion at the RCP.

The results and conclusions of the RCP will be communicated to you at a planned appointment with your haematologist, and not by telephone, so there is no point in your ringing to find out the outcome.

Your family doctor will also receive the treatment proposals and could explain them to you. Don't hesitate to talk to him or her.

If you wish to get a second opinion you can ask for the documents making up your medical record and duplicates of any correspondence from your specialist haematologist. He will be in a position to provide you with them.













------- Department of Clinical Haematology _______ Our Policy on Standards and Cell Therapy ______



The haematology department's medical and care teams have worked for a long time now to ever improve the quality and safety of their care of you during your illness. The department has focussed on the following areas:

Fighting pain

Pain is taken seriously by all the doctors, nurses and care staff in the department, whether it be pain associated with your illness or pain associated with the process of diagnosis, treatment or dressings. The medical staff assess your pain from the moment you arrive, and then repeatedly during your stay.

When invasive procedures are involved, you will be given documentation about the pain caused by blood tests or bone-marrow samples at the appointment when you are told of your diagnosis. We will offer you local patches or analgesia using KALINOX (a pain relieving gas) for any procedures you are afraid of.

Are you afraid of being in pain? Don't hesitate to talk about it to the team!

Whatever your pain, be it physical or psychological, do not hesitate to let the various staff members looking after you know. We are there to listen to you.



In the department, there are anti-pain procedures that are written down and accessible to all members of staff.

You may be offered a special consultation for your pain if it proves resistant to the treatments prescribed for you.

The CHU has an anti-pain committee that initiates awareness campaigns, and may be appealed to if you feel that your pain is not being taken seriously enough. Tel: 05 55 05 64 68).

Psychological support is also available to you: the psychologist, relaxation therapist and beautician can teach you to relax and will help you rebuild confidence in your own body.







Fighting Antibiotic-resistant Infections

Antibiotic-resistant infections can be contracted in hospitals and clinics. They may either be directly connected with treatment or simply occur independently of all treatment (e.g. during an influenza epidemic).

The department has written procedures accessible to all staff members.

Disinfectant dispensers are installed at the entrance to the department and each room for the use of your visitors as well as the staff.

The Limoges CHU has set up a committee to fight antibiotic-resistant infections (Comité de Lutte contre les Infections Nosocomiales or CLIN). It organises, coordinates and promotes all measures likely to reduce the risks of contracting such an infection in our hospital. It also



draws up a report of its activities and monitors data on the subject. This committee is made up of 22 members, including one tasked with the supervision of measures taken against these infections. ______ Department of Clinical Haematology _______ Our Policy on Standards and Cell Therapy ______





THE HEMATOLIM Network

The HEMATOLIM network – health professionals drawn together in a care network to coordinate your treatment and to care for you close to your home.

Introduction to the Network ------



Since 1994 the HEMATOLIM network has had as its principal aim to harmonise the care and treatment of blood-related disorders across the hospitals of the Limousin. Progressively, the Haematology Network of the Limousin, renamed the HEMATOLIM network in 1999, has taken on board a majority of the specific tasks of regional cancer networks as recommended by the National Cancer Institute (INCa) and the DHOS circular dated September 2007 relating to the organisation of cancer care.

Since 1999 an arrangement has been set up whereby visits can be made to haematology consultants, Dr M Touati and M-J Rapp, in local hospitals around the region, with the frequency of sessions matching the needs of patients at these hospitals, and with the aim of avoiding the necessity for patients to travel long distances to the centre they are referred to (Limoges CHU).

The task of the HEMATOLIM Network is to provide locally based care and access to specialist doctors, but also regionally based organisation and training of health professionals, and patient information. Its main task is to fight against inequality of access to care and to innovations in treatment.





Your treatment in the heart of the HEMATOLIM Network and associated hospitals and health centres

Your treatment is undertaken by the same team, but within a care network developed between the hospitals of the Limousin to enable your treatment to be carried out as close to your home as possible.

With close and regular links with the Limoges CHU reference point, the health professionals in the various hospitals and clinics carry out your follow-up: visits to the specialists, transfusions, antibiotic treatment, different treatments including even chemotherapy at different levels of intensity. Hospital stays at Limoges CHU only being necessary for intensive treatments, such as transplants, or where more specialised equipment, such as a PET scan, is required to monitor infections or for diagnosis.

The Network team is composed of :

- C. RIFFAUD (Administrative Coordinator) is responsible for the day to day management of the network, technical activity and communication.
- M. MUNYAMAHORO (Clinical Research Assistant) is responsible for assessment of the network and its professional practice and assists in the production of its publications.
- J. GARESTIER provides secretarial services and manages the HEMATOLIM Network's information documents.



In 2012, the HEMATOLIM Network was awarded by CPAM of the Haute-Vienne for the ESCADHEM plan (*Externalisation et de Sécurisation de Chimiothérapie injectable à Domicile pour les Hémopathies Malignes.*)



So that you do not have to travel to the CHU, appointments with specialist haematologists are available at various hospitals within the Network in the Limousin Region, either with Dr S LEFORT at Brive, or by the two Doctors of the HEMATOLIM Network, Dr M TOUATI and Dr M-J RAPP, by appointment.

Haematology appointments AWAY FROM THE CHU:

Centre Hospitalier de Brive par M^{me} Dr S. LEFORT, hematologist. (Medical secretary M^{me} ROSE - *Tél. : 05 55 92 60 52 / fax : 05 55 92 60 77*)

Specialist Appointments with Doctors in the Haematology Network in HAUTE-VIENNE:

- Centre Hospitalier de Saint-Junien. specialist appointments with Dr M TOUATI every Tuesday morning in collaboration with Dr J. VENOT, Dr. N. SIGNOL and Dr M. USCAIN (Secretary Mme A. DESSOLA - Tel. : 05 55 43 50 06 / fax : 05 55 43 50 82)
- Clinique Chénieux. specialist appointments with Dr M. TOUATI, every other Wednesday afternoon in collaboration with the rheumatology team: Dr J. VAQUIER, and Dr D. COYRAL (Secretary Mme C. COIFFARD-ROCHER Tel. : 05 55 45 44 44 / fax : 05 55 45 44 45).
- Centre Hospitalier de Bellac. specialist appointments with Dr M. TOUATI, once Wednesday afternoon a month in collaboration with Dr J. THEVENOT (Secretary Mme RAPIN - Tel. : 05 55 47 20 03 / fax : 05 55 47 20 37)
- Centre Hospitalier de Saint-Yrieix-La-Perche appointments with Dr J-B FARGEAS and Dr B VIGNERAS, and presentation of cases to the RCP by Dr J-B FARGEAS (Secretary – Tel: 05 55 75 75 20 / fax: 05 55 75 76 62)

Specialist Appointments with Doctors in the Haematology Network in CORREZE:

- Centre Hospitalier de Tulle. specialist appointments with Dr M. TOUATI every other Friday morning in collaboration with Dr P. LO RE and Dr M. GHICA (Secretary Mme V. MARTIN - Tel : 05 55 29 79 71 / fax : 05 55 29 86 36)
- Centre Hospitalier d'Ussel. specialist appointments with Dr M-J. RAPP, on Wednesdays every other week from April to October and Tuesdays and Wednesdays once a month from November to March in collaboration with Dr M-P. NORD-ROUBY. (Secretary Mme PONS Tel. : 05 55 96 43 21 / fax : 05 55 96 42 03)



Other hospitals take part in the HEMATOLIM Network which do not offer specialist appointments, providing appointments with General Practitioners who have been long trained in Haematology by the HEMATOLIM Network. These are:

Centre Hospitalier de Guéret appointments with Dr D. DEVESA and presentation of cases to the RCP (Multidisciplinary Medical Council) with Dr A. PENOT for the HEMATOLIM Network; (Secretary: Mme Marie-Line ROQUE and Michèle VIOLA – Tel: 05 55 51 87 20 / fax: 05 55 51 48 85).

Other hospitals take part in the hospital care without offering specific appointment.

- CHU Service de Médecine de Suite de l'Hôpital Jean Rebeyrol with Dr C. SOL-TOUATI (Tel: 05 55 05 65 20 / fax: 05 55 05 65 12)
- Centre Hospitalier de Saint-Léonard with the General Practitioners of Saint-Léonard (Tel : 05 55 56 43 00 / fax 05 55 56 43 22)



To contact the coordinator team for the network : **Réseau HEMATOLIM**

CHU Dupuytren – 2 avenue Martin Luther King 87042 LIMOGES Cedex Tél. : 05 55 05 60 63 (secretary) or 05 55 05 89 40 (coordinator) reseau.hematolim@chu-limoges.fr http://www.hematolim.fr





CLINICAL RESEARCH : An essential stage

From all time, improvements in medical knowledge and the treatment of illnesses have been the result of medical research contributed to by a large number of patients. It may be suggested to you in your turn, and depending on the nature of your illness and the stage it has reached, that you take part in a clinical research project.

Your participation in a piece of clinical research will only happen after its purpose, and any differences from the normal treatment in terms of blood tests, hospitalisation or treatment have been fully explained to you. As laid down in Law N° 2004-806 of the 9th August 2004, the proper practice will be followed in ensuring that your written consent is based on a full clear understanding.

You are free to take part in a study of your illness, or not to do so, and a refusal on your part will not change in any way how you are subsequently treated.

Why take part in a clinical research project?

To improve knowledge about the disease and its treatment.

So-called "Standard" treatments that you are offered, which are based on the current frames of reference have all been proven as the treatment of choice following previous clinical research projects in which other patients have taken part. For all that, despite medical progress, not all diseases can be cured at all stages and it is therefore important not to just be satisfied with standard treatments but to seek to improve our knowledge.

In a care department, research can take on different aspects. You may be invited to take part in:

Epidemiological or observational studies

- Epidemiological studies (studies of factors that affect diseases) in the form of observation. These studies aim to go into the frequency and the characteristics of certain diseases, their geographical distribution or their link with certain environmental risks.
- Studies of treatment of certain diseases with a view to studying the practice of their treatment.
- Medical protocols which evaluate the efficiency and the tolerance either of new medicines or new combinations of new drugs, or new administrative processes to see if the improvements hoped for as a result of small scale testing with a small number of patients is confirmed, as compared with the standard treatment, when applied to a large number of patients.

This research work is carried out involving groups of haematologists from several CHUs both in France and abroad (in national or international multi-centred studies), scientific societies and the pharmaceutical industry.

The law of 9th August 2004 covers biomedical research activities, and you may only take part on a voluntary basis and after you have been given full information by your doctor. It requires your signature of consent or of non-objection. For any questions you may have concerning a research project, you can approach the team at the Haematology Clinical Research Unit (Tel: 05 55 05 66 42).



Centres of Competence

The Clinical Haematology and Cellular Therapy Department has been nominated as a regional Centre of Competence for four rare pathologies:

- Thrombotic Microangiopathies.
- Auto-immune Cytopenia in Adults.
- Immune system deficiencies.
- Mastocytosis.

Centres of Competence network with the National Reference Centre for each pathology. The development of the network by identification of Centres of Competence has as its aim to develop local care and treatment in a homogeneous way and to facilitate access to information by the patient, the general public and by professionals through the ORPHANET website, through leaflets,



internet treatment cards (http://www.orpha.net/consor/cgi-bin/index.php?lng=EN) and promotion by the patient associations.

Prizes and Awards

2007 : Nominated Centre of excellence by The Myelodysplastic Syndromes Foundation.

Prix de santé publique de la Haute-Vienne, catégorie Recherche médicale, (URC-H), Amélioration de l'accès à la recherche clinique et à l'innovation des patients âgés de plus de 65 ans atteints d'hémopathies

- 2009 : Nomination aux Victoires de la Médecine (Pr D.BORDESSOULE) pour l'innovation intitulée « Un pessimiste voit la difficulté dans chaque opportunité, un optimiste voit l'opportunité dans chaque difficulté » W.Churchill, ou le Réseau HEMATOLIM :une réponse à l'inégalité d'accès aux soins, à la recherche clinique et à l'innovation thérapeutique dans la région Limousin.
- 2011 : 17ème congrès de la Société Française d'Accompagnement et de soins Palliatifs, Prix du meilleur poster discuté (Mme S. TRARIEUX – SIGNOL), « Regard d'un comité de patients sur la loi dite Léonetti »
- 2012 : Prix Robert et Jacqueline ZITTOUN sous l'égide de la FONDATION de France et de la SOCIÉTÉ FRANÇAISE d'hématologie (Dr S. MOREAU et al.)

1 er Prix de thèse et de mémoire de la fondation MACSF, catégorie cadres administratifs et directeurs (Mme S. TRARIEUX – SIGNOL) ; « Les enjeux éthiques de l'information des patients sur les résultats globaux de recherche thérapeutique dans le service d'hématologie clinique et de thérapie cellulaire du CHU de Limoges. »

2014 : PRIX EBMT nurses group du 40ème congrès international de l'European society for Blood and Marow Transplantation (L.TARDIEU) ; «National posttransplant follow up care logbook for patients undergoing allogenic hematopoietic stem cell transplantation : an initiative by the SFGM-TC.»

The Haematology Clinical Research Unit (URC-H)

The URC-H has twice received the Prix de Santé Publique du Limousin (the Limousin Public Health Prize): in 2007 for its role in "Improving access to clinical research and therapeutic innovation for sufferers from blood disorders" and in 2009 for the creation of a new line of human science research "Research focussed on patients in palliative care, an ethical and scientific process to do it better".

The department's IDE graft Coordinator received the prize for best poster award 2014 EBMT nurses group from the European society for Blood and Marow Transplantation for her project «National post-transplant follow-up care logbook for patients undergoing allogenic hematopoietic stem cell transplantation : an initiative by the SFGM-TC.»




The National Reference Centre for AL Amyloidosis

The National Reference Centre for AL Amyloidosis and other monoclonal immunoglobulin deposits diseases was awarded this status in 2006 in the context of the National Plan for rare diseases. **It is coordinated by Professor A JACCARD** and brings together the Haematology department of the Limoges CHU and the Nephrology department of the Poitiers CHU. The centre's principal objective is to improve and harmonise practice in the diagnosis and the treatment of patients with this rare disease.

There are 22 centres of competences spread across the French hexagon taking part in this harmonisation initiative.

The reference centre coordinates the clinical and fundamental research to do with AL Amyloidosis and other monoclonal immunoglobulin deposits diseases (new treatment protocols, a register of patients, animal models) and collaborates internationally with the principal European centres specialising in amyloidosis.

In order to facilitate access to information for patients and professionals, an internet site has been set up that you can refer to at the following address: http://www.cr.amylose-al.fr

You will find there information about the centre's activities, the diseases it treats and contact details for patient associations.



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



In the case of certain illnesses you may be asked to take part in a national, European or international clinical research protocol. You will then be given detailed information about the protocol and you will be asked to give your formal consent by signing a consent form.

In other instances, the treatment you will receive is regarded as «standard» for your disease as per current practice in the HE-MATOLIM network. There is no investigative protocol; your treatment will be explained to you in detail by the doctor. The Clinical Research nurse, Chantal TISSEUIL, will go over the detail of the treatment programme with you. Do not hesitate to ask any questions

that you need to in order to understand your illness and how its treatment is to proceed.

At key points in your treatment, the doctors and those who carry out your care are at your disposal to go over and explain any points that may seem complicated to you, so do not hesitate to approach them with your questions.

Information about the National IT and Freedom Commission (CNIL)

A certain amount of clinical, biological information, as well as information about your progress, will be recorded in IT that enable your treatment and what the department does to be evaluated. This data is recorded anonymously. The creation and use of these data banks

is subject to the CNIL's authorisation. All departments in the Limoges CHU use an IT system to help them manage patients' files and produce where appropriate statistical reports for the department's use.

*Articles 34 & 40, Law n° 78-17, 6th January 1978 concerning computer data files and liberty of information.





Information about use of biological samples for scientific purposes -

What is left over after samples have been tested (blood, bone marrow, ganglion or any other tissue involved in your diagnosis) may be used in the context of research into your illness. The results of the analyses carried out on these samples for scientific purposes remain strictly confidential and anonymous.

They may be recorded in IT programmes the creation and use of which are governed by the CNIL.

You are free to refuse to allow the use of the residual samples without it having any effect on your treatment, and if you do, we would ask you to fill in, date and sign a form of objection to the keeping and research use of biological samples. You will be able to keep the original (white) copy in your patient's handbook. Research laboratories check that there is no objection from you before using biological samples for research purposes.









WHAT ARE YOUR RIGHTS?



Direct access to your medical records

It is possible for you to receive the notes made at the time of your appointment with the doctor, your admission to hospital or to the day hospital simply by asking the secretaries. The majority of doctors dictate their minutes of the consultation in your presence and a copy can be sent to you if you wish. We would advise you to keep it in the plastic sleeves in this handbook. The main test results will be copied to you, so you can present a complete file in another hospital either within the HEMATOLIM network, or in case a complication should arise while you are travelling or on holiday, or to enable you to take a second opinion.

Moreover, since 2002, it has been possible for you to have access if you wish to your complete medical record¹. To do this you need only apply to head of the establishment indicating the department concerned and the doctor treating you. Any doctor you designate can also get to know the contents of your medical records.

Joint decision-making

Your expectations about your treatment will be taken into account. You can decide with the doctor treating you whether or not a given treatment is set in place, or continued, as well as whether additional tests are carried out¹⁺². It is important for you to talk these things over with your doctor.

Nominating a person you trust -----

If you wish, you can nominate a person you trust to be your "personne de confiance". You must do this in writing¹. If you need support, he or she can provide it throughout the length of your stay in hospital or for longer, according to your needs.

This trusted person may be a member of your family, a close friend or your GP.

The person you choose may at your request:

- Accompany you in hospital related administrative procedures.
- Be with you at medical appointments to help you take decisions.
- But will not receive information that you consider to be confidential.

The role of the "personne de confiance" does not go beyond this. He or she is not taking decisions in your place; it is you and your doctor who take decisions about your treatment.

In the event of your not being able any longer to express your wishes, and uniquely in this instance, your trusted person will be consulted by the hospital team about treatment that you might be led to receive or about taking part in a clinical research protocol.

¹ Law n°2002 - 303, 4th March 2002 concerning the rights of patients and quality in the health service ; Decree n° 2002-637, 29th April 2002

² Law n° 2005-370, 22th April 2005 concerning the rights of patients and end of life





The option is offered to you of designating a "personne de confiance"; there is absolutely no obligation to do so; however, nominating such a person may turn out to be useful in the case of patients with chronic illnesses.

If you do take up this option, talk about it to the person that you have chosen to ensure that he or she is willing to accept this role, and that he or she is in a position to express your point of view should this prove to be necessary.

Preparation of Advance Health Care Directives (Living Wills) ------

Whether your illness is benign or malignant, in order to make known your wishes concerning the end of your life, you may prepare Advance Health Care Directives ².

As it is not easy to contemplate the end of one's life nor to imagine a day coming when you would not be able to express your wishes, the law offers the possibility of thinking about it in advance.

Try and talk it through with your nearest and dearest, this is the best way to make known your views.

Living wills may be written by anyone who wishes to make known their wishes about the end of their life and circumstances under which treatment might be limited or halted.

They can be revoked at any time and are only valid for a period of 3 years. The doctor takes it into account when

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making any decision regarding investigation, intervention or treatment of the patient. There is no compulsion to produce them, but they will serve to indicate your wishes to the medical team treating you.

Various members of the team are at your disposal if you have any questions or if you wish to discuss this with them.

On your arrival in the department you can make known who you are nominating as your "personne de confiance" and give your living will to a member of the team. A blue form has been made available for this purpose.

The regional haematology patients committee

The Patients Committee was created in October 2008 by a dozen or so patients, former patients and relatives of patients as part of a move to continuously improve quality and the experience of patients in the department. This is in response to recommendations in the Cancer Plan 2003-7 ("Social and Information section: Patient Follow-up") and 2009-13 (measure 19).

It is chaired by Sophie TRARIEUX-SIGNOL, clinical research technician in charge of human science research in the department.

The role of the Patient Committee is to involve those using the department, through an exchange of views and advice about the different aspects of treatment and everyday life in the department based on their experience, in the steps taken by the care team to improve quality.

As an example, all information documents put together by the care team are submitted to the committee for approval, such as this booklet (presented at Committee meetings on 20/01/09 and 24/11/09).

The Patients Committee also takes part in choosing how to use donations to make the life of patients within the department more pleasant.

Its role extends to a consultative input into the areas for clinical research carried out within the department.

If you would like to get in touch with the Patient Committee with suggestions for things to be done or if you would like more information, you can contact Sophie TRARIEUX-SIGNOL (Tel: 05 55 05 88 64 ; comitepatientregionalhematologie@chu-limoges.fr).



■ Recently, the Limoges CHU has equipped itself with a meeting place for users of the hospital ("Maison des Usagers" near Reception and the Main Entrance) in order to promote patients' rights, but also to recognise what former patients and their near ones have to offer patients in the social and health domains and in the improvement of the care and treatment. Different Patient associations hold drop-ins there. You can meet volunteers from La Ligue contre le cancer, as well as members of the User Relations and Treatment Quality Committee (CRUQPC).



Patients' Associations

You can if you wish contact volunteers from patient associations. In presentation cabinets in the waiting rooms of the department, you will find leaflets from:



http://www.alte-asso.org/fr/index.html

And plenty of others...

The French Haematology Society and the HEMATOLIM network keep information sheets available to you covering all diseases treated by haematologists. These documents will be handed to you by the doctor at the appointment when you are told of the diagnosis. If that has not happened, do not hesitate to help yourself from the display shelves in the waiting rooms and to have any points you don't understand explained to you by your haematologist.

These documents are also available for dowload on the HEMATOLIM website at the address http://hematolim.fr/fr-fr/informationgrandpublic/documentsenanglais.aspx





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Patients' Families and Friends

Patient's families and Friends

Department of Clinical Haematology

83

and Cell Therapy



At appointments with doctors in the department, or at the appointment at which you are told of the diagnosis, or when test results are being shared with you, don't hesitate to come with your "personne de confiance" – the person you have nominated as your trusted person (see page 78 in the section "What are your rights") or a member of your close family or a carer. This means you will not be alone at a time when you hear news that can sometimes be distressing and those close to you can best support you.

Doctors meet the families of people in hospital every day after 5.30pm without the need for an appointment to see an intern, or by appointment from the secretaries (available from 8am to 5pm), where a senior doctor is concerned.

Who is regarded as a person close to you?

A person close to you is someone, family member or not, who, when they act legally, do so in the patient's interests and not his own.

Information for Families

Laws about medical confidentiality militate against information about a patient's state of health being given to third parties, which those close to the patient still are. Violation of patient confidentiality is a criminal offence where a doctor or any other professional is concerned. However, legal exceptions exist where it can be shown they are necessary in the light of the patient's wishes or his state of health.

It will be you who decides who, amongst your family and friends, you will allow to know any information relating to your illness.

On you arrival, or at your initial appointment, a nurse will hand you the "patient information sheet", coloured blue. Please complete it; you can be helped to fill it in if you need it.

In order to avoid potential arguments, if you nominate a "personne de confiance" it may simplify the relations between your family and friends and the care team. If one day you are no longer in a position to express your wishes, the person you have nominated will be the person who the care team will first turn to.

If it turns out that your "personne de confiance", a member of your family or someone close to you has to be consulted, the doctor will take account of the opinion expressed, but

is nonetheless not bound to follow it, and remains accountable for his choice. The health professional provides the information to the near one orally. The latter does not have access to the patient's medical records.

In the context of biomedical research, and only in case of emergency, where the consent of the patient has not been obtainable beforehand, the consent of the "personne de confiance" or the family will be sought.







In certain cases, the close person may have a right to time off work in order to help the patient.

Family Solidarity Leave

Any employee whose child, parent or other person sharing his home suffers from an illness where the prognosis is serious has a right to Family Solidarity Leave.

This leave may, if the employer agrees, be turned into a period of part-time working. In order for this to happen, the employee must apply to his employer in writing and by registered letter enclosing a medical certificate relating to the person he will be caring for.

In case of emergency established in writing by the doctor treating the patient, this leave may begin without delay, the moment the employer receives the letter.

This leave, which is not paid, and which lasts up to 3 months, may be renewed once. At the end of the leave, the employee regains his post or an equivalent post along with his former pay, and benefits from advantages linked to his seniority in the job, for which the leave is taken into account.

Family Support Leave

An employee who has worked at a firm for a minimum of 2 years has a right to leave when his or her spouse, partner, PACS partner, child or parent, child in his charge, cousin at some remove, who is resident in France and not placed in an establishment or in the home of a third party other than the employee, has a disability or a loss of ability to care for him or herself of a particular order of seriousness.

The employee makes a written application to his employer sent by registered post at least 2 months before the leave is to start, in which the dates for the beginning and the end of the leave period are stipulated.

In emergencies the period of notice can be reduced to 15 days.

This application must be accompanied by a declaration made on one's honour of the relationship with the person being helped.

■ If it concerns an adult disabled person: a copy of the decision from Social Security that the level of impairment is at least 80%.

■ If it concerns an inability to care for oneself: A certificate of entitlement to the Allocation Personalisée d'Autonomie (APA) (approximately equivalent to DLA).

This unpaid leave, initially for 3 months renewable, may not be taken for more than a year in the whole working life of the employee. Throughout the period, the employee may not work, though he can be employed by the person he is helping. At the end of this leave, the employee goes back to his former post or an equivalent.







FINDING OUT MORE







Blood : What is it ?

Blood* is a liquid that runs through blood vessels in our body. It consists of red blood cells*, white blood cells* and platelets* suspended in a transparent yellow fluid called the serum or plasma made up of a mixture of water and various proteins.

How much is in the body ?

On average, adults have 5 litres of blood in their body though this varies between individuals. The quantity of blood taken in samples is 3 to 7 ml (millilitres).

Monitoring your condition in hospital requires numerous samples of blood so to minimise the quantity taken for tests, our specimen tubes are all undersized paediatric tubes normally only employed on children's wards.



* Words preceded by an asterisk refers to its definition in the glossary p. 98.



Constituents of Blood

• **Red blood cells*** (RBCs), also known as erythrocytes, contain haemoglobin* and transport oxygen and carbon dioxide between the lungs and body cells. There are about 4.5 million red blood cells in every cubic millimetre, responsible for the red colour of oxygenated blood.

Haemoglobin levels on average are higher in men (14g/dl) than women (12g/dl). A surplus of red blood cells is known as <u>polycythaemia or erythrocytosis</u> (fr. polyglobulie), whereas a deficit of red blood cells leads to <u>anaemia</u>*, a condition in which patients feel out of breath or weak due to low levels of oxygen-carrying haemoglobin in their blood.



Finding out more

Department of Clinical Haematology

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and Cell Therapy



- White blood cells* (WBCs) or leukocytes, vary in numbers between 5,000 and 10,000/ mm3 in healthy individuals. When you have a blood count (numération formule sanguine or "NFS"), an estimation will be made of the relative numbers of different types of leukocytes in your blood as determined visually under the microscope. Each type has a specific function, listed below :
 - Granulocytes or polymorphonuclear leukocytes (neutrophils) are the most abundant sub-group of leukocytes at roughly 4,000 to 8,000 per mm3 of blood. The actual level depends on age, stress, exercise and state of digestion so it is always important to have blood samples taken when feeling relaxed, several hours after your last meal and not after any physical exertion. Values should be determined in a single laboratory as the levels can vary significantly from one testing centre to another.

Raised numbers of neutrophil polymorphonuclear leukocytes, a state termed <u>neutrophilic hyperleukocytosis</u>, occurs when the body needs to fight bacterial infections (e.g. a cold or a urinary tract infection).

Low numbers of neutrophils, a state known as <u>neutropaenia</u>*, or their virtual depletion (<u>agranulocytosis</u>), puts the sufferer at great risk of catching an infection by bacteria. [Advice on how to deal with this condition is given in the section on aplasia.]

Two other varieties of polymorphonuclear leukocytes, the eosinophils* and basophils* are much rarer and less implicated in the body's defences against bacteria.





- Monocytes or tissue macrophages defend the body in the same way that

granulocytes do, by engulfing and killing bacteria as well as abnormal cells.

- **Lymphocytes**, the third and most sophisticated type of white blood cell, play a key role in the immune system, protecting the body against infection by recognising viruses, cancerous or dysfunctional cells and foreign particles. They are helped by granulocytes and monocytes which pass them digested fragments of bacteria or rogue cells so lymphocytes can better target immune responses.



Two types of lymphocyte have been identified, T cells and B cells, with an overall count of 2,000 to 4,000 per mm3 of blood, i.e. half the concentration of polymorphonuclear leukocytes.



Infection by, for example a virus like the cytomegalovirus that causes mononucleosis immediately causes proliferation of lymphocytes, recognisable by their characteristic single nucleus. When levels of lymphocytes fall, the body's defences are low, a state known as immunodepression associated with high frequency of viral and fungal infections.

• **Platelets or thrombocytes** are small cell fragments (without a nucleus) that play an important part in haemostasis, the stopping or limiting of bleeding through coagulation. Platelet levels range from 250,000 to 500,000 per mm3 of blood.

Excess platelets (<u>thrombocytosis</u>) may lead to thrombosis in which clots block blood vessels. Low platelet numbers (<u>thrombocytopaenia</u>*), result in spontaneous bleeding under the skin, <u>purpura</u>*, bruising, nosebleeds or bleeding in the gut. You should inform your doctor if you observe any bleeding since this can be remedied by a transfusion* of platelets.

What does the blood do ?

Red blood cells are by far the most common celltype in blood (99%). However, their biconcave disk shape and lack of a nucleus make them unusual for cells. They could almost be considered as highly flexible "packets" of the iron-containing molecule, haemoglobin, which enables oxygen to be transported to cells in the body. Different proteins on the outer membrane provide the basis for identification of blood groups (*types A, B, AB, O, Rhesus +/- ...*). Red blood cells survive in the circulation for about 120 days, forming in the bone marrow (*where most blood cells originate*) and dying in the spleen. Making of red blood cells,



known as *Erythropoiesis*, is stimulated by a hormone called erythropoietin released by the kidneys when oxygen levels are low. This same <u>erythropoietin</u> (*EPO*) can be synthesized by pharmaceutical companies and prescribed as a therapeutic drug, ...or in the case of cyclists, used to boost your metabolism... But that's another subject altogether!

• White blood cells (polymorphonuclear leukocytes and monocytes) constitute the body's principal means of defence against infectious diseases. They destroy microbes by *phagocytosis*, a process of engulfing offending invaders and then digesting them with enzymes. Ingestion capacity has its limits though, and after a while the white cells *burst*, releasing half-digested microbes and cell fluids which we recognise as puss. Simultaneously, the exploded cells release *cytokines* that act as chemical messengers to attract more white blood cells to the site of infection and finish the job. If overwhelmed, further chemical messages can be sent to call for cells which have a different method of combating microbes. All this activity produces a fever in the infected person plus localised reactions such as redness, heat, swelling and pain. When leukocyte and monocyte levels are low, infection can therefore start without the tell-tale presence of puss or any other warning signs so it is vital to alert your doctor even if your symptoms seem minor.









Bone Marrow

What and where is it?

Circulating blood cells generally all start their life in bone marrow*, the spongy cavities of bones, especially in the flat bones of the breast (sternum) and pelvis (ilium). Two types of marrow can be observed; red marrow containing blood cells in various stages of formation and yellow marrow mostly made of lipid cells (in adults). Less productive in older people, the average volume of bone marrow in an adult amounts to 3 to 4 litres, of which 1.5 litres is active red marrow.

Taking samples?

Two main methods are used to obtain samples of bone marrow:

- Taking a sternal marrow aspirate consists of piercing the sternum (breastbone) and extracting a small quantity of marrow cells that can then be studied in a laboratory to give a reading of their type and stage of development (in french, "<u>myélogramme</u>").

- <u>Pelvic bone biopsy</u> (in french, "biopsie sur l'os



iliaque") consists of removing a small core of marrow and bone from the pelvis. This provides a good cross-section of internal structure, thin slices being prepared and stained for microscopic examination in a laboratory.

What goes on inside the bone marrow?

Bone marrow is not only where white blood cells are made but also where erythrocytes (red blood cells) and platelets develop. Since erythrocytes survive for about 120 days, leukocytes for 2-10 days and platelets just a few days depending on how quickly they form a clot and are broken down, the process of forming new blood cells (haematopoiesis) is vital to maintain normal levels in the body.

The mechanism starts with a small number of *undeveloped* cells called <u>haematopoietic</u> <u>stem</u>* cells which divide and multiply in bone marrow eventually producing the millions of cells that circulate in our blood.



Each division doubles the population derived from a single haematopoietic stem cell (2, 4, 8, 16, 32, 64, 128, 256...) and as the daughter cells propagate and mature they also undergo differentiation into specific types of blood cells, each type promoted by its own specific stem cell growth factor (SCF) that influences its genetic development:

- Erythropoietin encourages stem cells to develop into red blood cells.
- G-CSF (*granulocyte-colony stimulating factor*) makes the cells become granulocytes.
- Thrombopoietin turns stem cell lines into platelets.

Research has led to a number of SCF-derived drugs that can be used to stimulate regrowth of bone marrow damaged through illness or as a side-effect of chemotherapy. These products stimulate production of specific blood cell types in the marrow (e.g. Neupogen and Granocytes act like G-CSF in activating granulocyte production, while Eprex®, NeoRecormon® or Neulasta® imitate erythropoietin-induced red blood cell production). However, any success in regenerating marrow ultimately depends on the health and viability of the original stem cells

Bone Marrow Donors ?

Bone marrow stem cells can be taken from a healthy donor and injected (like a transfusion) into patients who have previously undergone intense chemotherapy or radiotherapy to destroy their own bone marrow cells. Compatibility between donor and receiver is vital; there is a one in four chance of brothers and sisters having the same HLA profile whilst for donors outside the family compatibility chances drop to as low as one in tens of thousands.



The Lymphatic System

Swollen superficial lymph nodes can easily be detected by palpation of the neck, armpits and groin areas. Deep lymph nodes however, require diagnosis by X-ray or CT scans; for example a chest X-ray or chest scan for lymph nodes in the thorax, an ultrasound and/or CT scan for abdominal or pelvic lymph nodes.

What is a lymph node?

Lymph nodes are oval or bean-shaped nodules along the lymph ducts. They act as filters, removing harmful particles from the lymph through a mechanism involving macrophage* cells that trap and digest bacteria. The digested fragments are then presented to lymphocyte* cells in the lymph node so they can make antibodies to those specific bacteria. The antibodies then work by fixing themselves to their target bacteria and triggering a series of reactions that results in their destruction and elimination. This often happens in the spleen.

This is why during infections, as lymphocyte numbers increase, lymph nodes tend to swell and can be felt by touch as hard lumps ("lymph glands") before reducing in size as the infection passes.

A large swollen lymph node that persists without any apparent illness (lymphadenopathy) can have many causes, one of which is abnormal proliferation of lymphocytes. A sample or biopsy may have to be taken to determine whether this is due to a malignant lymphoma, Hodgkin's disease, viral or bacterial infection of the node itself or other causes... it should be remembered that large lymph nodes are not systematically due to tumours.

Extent of the lymphatic system?

The lymphatic system spreads throughout the body in parallel to the cardiovascular system, linking lymph nodes, lymphatic glands and organs within a circulatory network of lymph vessels. Three elements make up the system :

- Lymph; a watery liquid originating from interstitial fluid (i.e. the fluid between cells in body tissues).
- Lymphatic vessels; the ducts through which lymph and lymphocytes* circulate.
- Lymphoid tissue; organs or structures where lymphocytes are stored or mature (lymph nodes, spleen, thymus gland, tonsils etc...).



What is its function?

The lymphatic system has several roles.

1. As a drainage system, it removes excess interstitial fluid. (Manual lymphatic drainage for example, is a therapeutic technique that exploits this, using massage to reduce tissue swellings).

2. Fats and certain vitamins are distributed throughout the body via lymphatic vessels.

3. Most importantly, as described above, the system provides a means for white cells to encounter and identify invading organisms such as bacteria and viruses as well as abnormal (e.g. tumour) body cells, consequently triggering a targeted immune response with efficient communication between lymphocytes*.

What is the "immune response"?

The Immune Response is a cascade of events that the body puts in place when it is attacked by a virus or bacteria or when it detects an abnormal cell (cancerous cell). This requires an interaction between white corpuscles T.



Glossary

- Anaemia (Anémie) : refers to a condition where the body has abnormally low numbers of red blood cells. In clinical terms this is defined as a decreased level of oxygen-binding haemoglobin*. The consequence is that less oxygen reaches body tissues provoking symptoms of tiredness, a pale complexion, feeling out of breath etc. It should be noted that clinical signs like these are more related to the speed anaemia develops than its seriousness. If onset is slow, the body will have time to adapt and symptoms will be mild. Platelet* count and white blood cell* levels may be normal or not, depending on the type of anaemia.
- Nutritional anaemia (anémie carentielle) : is caused by vitamin B12 or folic acid deficiency which interferes with DNA synthesis. This can easily be corrected by injections of B12 or by taking folic acid tablets.
- Microcytic anaemia (anémie microcytaire) : is a general term to describe anaemias with smaller than normal red blood cells.
- Macrocytic anaemia (anémie macrocytaire) is said to occur when red blood cells are larger in size than normal.
- Iron-deficiency anaemia (anémie ferriprive), : the most common form of anaemia, results from lack of iron essential to making haemoglobin. A course of iron-rich tablets can normally correct this imbalance.
- Refractory anaemia (anémie réfractaire) : is an anaemia that cannot be cured by supplements of iron or vitamins. It is caused by malfunctioning stem cells in the bone marrow failing to develop correctly into normal blood cells.
- Alopecia (alopécie) : means temporary hair loss or going bald, often a side-effect of chemotherapy and other treatments.
- Asepsis (asepsie) : is the absence of pathogens. Aseptic technique covers a range of measures designed to eliminate or prevent infections by contact with germs, particularly in a hospital or surgical environment. These might include amongst others, washing hands, wearing a face mask, surgical gown, sterile overshoes and mob cap.
- Basophils (basophile) : belong to the white blood cell family of granulocytes (or polymorphonuclear leukocytes), so-called because of granules that can be seen under the microscope. Basophils (making up 0.5 to 1% of the total number) have granules that stain with base (alkaline) dyes. The other granulocyte types are eosinophils* (staining pink with acidic eosin dye) and neutrophils* (neither acid nor base dyes stain well) which are the most common.
- Blood cells (cellules sanguines) : are a range of cells that circulate in the blood. They include red blood cells, white blood cells and platelets.
- Stem cells (cellules souches) : are unspecialised ("undifferenciated") cells with the inherent ability to become any type of specialised cell in the body (i.e. they are "pluripotent"). Bone marrow in humans contains stem cells that grow, multiply and develop into the various cells that make up our blood, differentiating into one type or another under the influence of specific growth factor molecules.
- Stool cultures (coproculture) : are carried out on samples of faeces to identify bacteria causing an infection. The test involves observation of cultures under different growing conditions and antibiotic treatments.



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- Diuresis (diurèse) : means the discharge of urine and in particular, passing a more than normal volume.
- Urinalysis (ECBU): if complete, involves cytological and bacteriological analysis of a urine sample to identify the strains of any infecting bacteria. This type of sample is sometimes called a clean-catch specimen and must be preceded by cleansing of the genital area and hands to avoid contamination. During aplasia (halted production of blood cells), urinary tract infections can occur without traces of leukocytes in the urine.
- Sputum culture tests (ECBC) : enable identification of bacterial or viral infections of the lungs and bronchi.
- Erythrocytes (érythrocyte) : is an alternative name for red blood cells* (RBC) or red blood corpuscles.
- Eosinophils (éosinophile) : are a type of white blood cell* that stain orange-pink with eosin dye. They represent 2 to 4% of all white blood cells and play a role in allergic reactions (releasing histamin). (cf. Neutrophils, Basophils.)
- **Erythropoietin (érythropoïétine) :** is a hormone made in the kidneys when oxygen levels decrease. It stimulates the bone marrow to produce more red blood cells.
- Erythropoiesis (érythropoièse): is the term used to describe formation of red blood cells (erythrocytes) from precursor stem cells in bone marrow. The process is stimulated by the natural hormone erythropoietin (EPO) which circulates in the bloodstream.
- Laminar Flow (flux laminaires): Rooms said to have laminar flow systems are merely rooms that have high levels of protection enabling aplastic patients to avoid contamination from outside. The laminar flow systems form part of a ventilation system separated from the ventilation of the rest of the hospital. Air drawn from the 6th floor is pre-filtered and then filtered for a second time just above the patient. This second filter retains particles smaller than 0.2µ and thus protects the patient from infectious agents, especially fungi that he or she might encounter outside the flow. These laminar flow systems, some of which date from the 1970s are regularly maintained, with the filters being changed annually. Hospitalisation in a laminar flow area does not mean that the patient is isolated and that any visiting is not allowed: visitors are allowed, but remain outside the curtain. Within the laminar flow area, all equipment is disinfected and the water used for washing is filtered. If you need additional examinations or tests, you may come out of the laminar flow area, but always wearing a mask.
- White blood cells (globules blancs): number between 5,000 to 10,000 per mm3 blood. They constitute the body's defence mechanism against infections (immune response) and are also implicated in allergic reactions.
- Red blood cells (globules rouges) : transport oxygen from the lungs to the body cells and evacuate carbon dioxide from cells back to the lungs. Their concentration in the blood varies between 4 and 5 million per mm3.
- Haematology (hématologie): covers areas of science and medicine concerned with the study of blood and its disorders, including benign or malignant function of bone marrow and the lymphatic system.

Glossary

- Haematopoiesis (hématopoïèse) : is the process of forming blood cells. It takes place in the marrow of certain bones where precursor stem cells grow into red blood cells*, white blood cells* and platelets.*
- Haemoglobin (hémoglobine) : an iron-containing pigment found in red blood cells, gives them their red colour and binds to oxygen in the lungs before releasing it as the blood passes through capillaries in body tissue. Haemoglobin also aids transport of CO2 from the tissues to the lungs.
- Leukocytes (leucocytes) : another name for white blood cells*.
- Leukopenia (leucopénie) : means a low white blood cell count*.
- Lymphocytes (lymphocyte) : care a specific type of white blood cell and play a vital role in the immune system.
- Macrophages (macrophage) : are a specific type of white blood cell that develops from monocytes in bone marrow before becoming a tissue macrophage, engulfing and killing bacteria (a process called phagocytosis*) in the body's tissues.
- Monocytes (monocyte) : account for 2 to 6% of all white blood cells. They develop from stem cells in the bone marrow before migrating via the blood stream into body tissues, where they continue their existence as phagocytic* macrophages*.
- Bone marrow (moëlle osseuse): the soft core of bones, is the site of haematopoiesis*, i.e. blood cell production.
- Neutropenia (neutropénie) : means a reduced numbers of neutrophil* granulocytes*.
- Neutrophil granulocytes (polynucléaires neutrophiles) : also called neutrophil polymorphonuclear cells or PMNs, are the most common type of white blood cell, representing 60 to 70% of the total number. They help fight infections by ingesting and destroying bacteria (phagocytosis).
- Perfusion (perfusion) : or more commonly "being put on a drip" generally refers to the technique of giving medication intravenously via a catheter, infusion tubing and syringe. It should not be confused with the term, transfusion*.
- Phagocytosis (phagocytose) : is the technique macrophage* cells employ to destroy bacteria or other invading organisms. It consists of flowing around and engulfing the target bacteria, which once inside the macrophage, can then be broken down by enzymes into inoffensive fragments.
- Platelets (plaquette) : are small granulated cell fragments. They contain molecules that cause clotting of blood and plug bleeding wounds.
- Premedication (prémédication) : is given to patients before administering painful, uncomfortable or potentially allergenic treatments, so as to avoid or reduce potentially unpleasant side-effects and reactions.
- Purpura (purpura) : is a condition characterised by the appearance of bruise-like purple or red blotches and spots, often occurring on the legs, around the waist and upper torso. They are caused by haemorrhages in and under the skin and you should urgently ask for a blood test in case this is due to a lack of platelets in the blood.



- **Blood (sang) :** is a physiological liquid made up of plasma and blood cells*.
- **Splenomegaly (splénomégalie) :** is the medical term for an enlarged spleen.
- **Thrombocytes (thrombocyte) :** an alternative name for platelets.
- Thrombopenia (thrombopénie) : signifies a low platelet* count and can cause purpura*.
- **Transfusion (transfusion) :** is the intravenous injection of a blood-derived product such as packed red cells*, platelets* or whole blood.







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Haematology Department Contacts

Pr Bordessoule – Dr Gourin 05 55 05 66 42 Dr Turlure – Dr Girault 05 55 05 80 39 Pr Jaccard – Dr Abraham 05 55 05 66 51 Dr Moreau – Dr Dmytruk – Dr Penot 05 55 05 80 38 Dr Reménieras 05 55 05 89 75 **Dr Touati** 05 55 05 60 63 Appointments : 05 55 05 66 52 In-patients : 05 55 05 67 55 Day-patients : 05 55 05 66 62







Thanks are due ...

- To the generous donors: patients and former patients in the department, those close to patients, associative clubs (LIONS and especially the CELADON Club) thanks to whose donations we have been able to equip patients wards with HiFi and video systems for free, and exercise bikes, to decorate the wards and to serve meals in nice crockery.
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This English-language version has been made available on demand to English-speaking patients. The translation was carried out by two members of the Regional Haematology Patients' Committee : Mr A. BILLINGTON, and Mr R. WARE, also volunteer of Cancer Support France Haute-Vienne, whom we warmly thank for this work. The technical support was carried out by Mr O. CHICAUD.

This document was updated by the team of the Clinical Haematology and Cellular Therapy department of the Limoges CHU.

The English language version of this document was validated on 13/08/2014

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Evaluation of this Haematology Patient's handbook.

Dear patient,

In order to improve this information handbook, we would be grateful for your comments and observations both on its content and the format. Please tell us if this document met with you expectations. It is also possible that we have left out information that you feel should be there. Please make any suggestions you may have about ways we might improve it.

Please hand this page in to the Haematology Clinic secretaries, on the 6th floor, opposite Lift C, for the attention of Sophie TRARIEUX-SIGNOL

The Team at the Haematology Clinic at the Limoges CHU.









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Department of Clinical Haematology and Cell Therapy tél. : 05 55 05 66 42

C.H.U. Limoges

2, avenue Martin-Luther-King 87042 LIMOGES CEDEX

