

# **Oncology/Haematology & Bone Marrow Transplant Unit- St. John's Ward.**

- 📁 Welcome page
- 📁 Introduction
- 📁 Clinical Services
  - 📁 Services offered
- 📁 St. John's Ward
  - 📁 The National Paediatric Haematology/Oncology Project
  - 📁 Medical Tower Building
  - 📁 Minor Works
- 📁 Medical staff
  - 📁 Introduction
  - 📁 Oncology Team
  - 📁 Haematology Team
  - 📁 Non-consultant Hospital Doctors
- 📁 Nursing Staff
  - 📁 Introduction
  - 📁 The IV Team
  - 📁 The Clinical Nurse Specialists
    - CNS Parent Educator
    - CNS Haematology/Oncology
    - CNS Bone Marrow Transplant Co-ordinator
    - CNS Haematology
    - CNS Haemophilia
    - CNS Haemoglobinopathy
- 📁 Clinical Nurse Specialist Service
  - 📁 Introduction
- 📁 Shared Care Centres
  - 📁 Other link Hospitals
- 📁 Research Nurses
- 📁 Patient Information
  - 📁 Patient Information on Cancer
    - Introduction
    - Children diagnosed with cancer at OLHSC between 1993 & 2003
    - Childhood cancers at OLHSC between 1999 & 2003
    - Common Childhood Cancers
      - Leukaemia
      - Lymphomas
      - Wilm's Tumour
      - Neuroblastoma
      - Bone Tumours

- Brain Tumors
- Rhabdomyosarcoma
- Other Tumors
  - Germ Cell Tumors
  - Histiocytosis
  - Retinoblastoma
- Cancer Information & Support Services for Families
- Patient Information about Haemophilia
- Patient information about Haemoglobinopathies
  - Definition
  - Thalassaemia
  - Sickle Cell Disease
- Patient information about the anaemia's
  - What is anaemia
- Barretstown- Magic for Families

# The Haematology/Oncology & Bone Marrow Transplant Unit.

Welcome to St. John's Ward.



## Contact us:

<b>Telephone:</b>	01.4096100/6654
<b>Fax:</b>	01.4563041
<b>E-mail:</b>	st.johns@olhsc.ie
<b>Location:</b>	St. John's Ward

# Introduction Oncology/Haematology &H.S.C.T.



## **Introduction**

St John's Ward is home to Ireland's national referral centre for Paediatric Oncology/Haematology and Haemopoietic Stem Cell Transplantation (HSCT).

The development of the National Paediatric Oncology/Haematology service is now being completed at Our Lady's Hospital for Sick Children. The final transfer of services took place on the 17<sup>th</sup> May 2004 with all patients with Haemophilia and Related Coagulations disorders attending OLHSC. The transfer of Haematology services completes the development of a comprehensive Oncology/Haematology national service for the following patients:

- 1) Oncology
- 2) Malignant Haematology
- 3) Non-Malignant Haematology
- 4) Haemoglobinopathy
- 5) Haemophilia and Related Coagulation disorders
- 6) Haemopoietic Stem Cell Transplantation.

Children diagnosed with cancers and haematological disorders do require special attention and treatment, however new and better ways of treating these conditions are being discovered every day.

# Clinical Services

## Clinical Services

Our clinical services cover the diagnosis and treatment of all forms of childhood cancers and leukemia's. Screening, diagnosis and management of the Haemoglobinopathy and Coagulation Disorders are now also managed from our unit.

Here in the Oncology/Haematology Unit we take a multi-disciplinary approach, to the care of the children we look after. We try to understand their needs and the needs of their families, seeking to provide the highest standards of possible quality of care and services.

### Services offered:

- 🌐 diagnostic services or tests to find out more about the child's type of disorder
- 🌐 contact with the three Dublin maternity hospitals to provide screening for those at risk of hereditary Haemoglobinopathy and Coagulation Disorders
- 🌐 dedicated Inpatient Ward for acute care
- 🌐 immediate, 24 hour Day Ward, walk-in access for acute care
- 🌐 outpatient treatment centre for ongoing management and support care
- 🌐 bone marrow transplantation service
- 🌐 psychological and support services
- 🌐 palliative care and bereavement support
- 🌐 education of parents/families and health professionals
- 🌐 clinical research and clinical trials, including participation in the research trials of the (UKCCSG) United Kingdom Children's Cancer Study Group.

## St. John's Ward

### St. John's Ward

St. John's Ward presently accommodates the majority of our In-patient and Day Ward services as the National Paediatric Oncology/Haematology service continues to be developed at Our Lady's Hospital for Sick Children. The ward has 18 in patient beds including two laminar flow rooms for Haemopoietic stem cell transplant patients plus a six-bedded Day Ward facility.

The ward also includes:

- ☒ A.C.U. - the Aseptic Compounding Unit which prepares all our cytotoxic drugs along with all our prepared Intravenous antibiotic / antifungal /antiviral drugs.
- ☒ C.S.U. – the Cell Separator Unit which collects platelets from volunteer donors, and provides essential therapeutic apheresis for inpatients

While building work progresses we are gratefully assisted in the care of our patients by:

- ☒ St. Michael's Ward- provide bed space for the non-malignant haematology in-patients
- ☒ St. Vincent's Ward- provide bed space for the non-malignant haematology day cases
- ☒ Out patients- provide clinic space for all of our out-patient requirements while the building of the Medical Tower is being completed

## **The National Paediatric Oncology/Haematology Development Project**

### **The National Paediatric Oncology/Haematology Development Project**

Our new extension of approx 5,500 sq ft (550 sq metres) has been approved by the Dept of Health & Children. This new area will accommodate

- a) A new 12 bed Day Care Service
- b) 6 beds for Non Malignant Haematology
- c) Extension to the Apheresis Unit and upgrade to IBTS standards
- d) Clinic rooms
- e) Office Facilities
- f) Ancillary offices and storage.

The Design Team has been appointed and is presently preparing detailed drawings and plans for approval by the hospital and the local authority planning dept. As the site is in the vicinity of St John's is a very restricted one it is intended that a modular build be used which would help shorten the building time as against a conventional style. The planning process will take 3 months so we expect that the new extension would be available for occupation in the spring of 2005.

### **Medical Tower Building**

The new medical tower presently under construction will accommodate the Ambulatory care service for Oncology/Haematology on the 3<sup>rd</sup> floor level. This development will consist of a floor area of 1800 sq ft and will include;

- a) Clinic rooms/out patient rooms
- b) Phlebotomy room
- c) Nurses office
- d) Reception and patient waiting area
- e) Consultant offices
- f) Administrative offices
- g) Conference rooms
- h) Telemedicine suite

It is intended that the building works will be complete by end of August 2004 and that the OPD department of Oncology/Haematology will be on site by end of September/early October 2004.

### **Minor Works**

Other minor works have taken place in the recent months to meet the ongoing challenge of the needs of an ever expanding service.

These included:

- a) the conversion of offices to clinic rooms in St John's,
- b) the relocation of medical records storage to a central location on the ward to accommodate newly appointed data managers,
- c) alterations, new equipment and upgrades to areas of St Michaels and St Vincent's wards to accommodate transfer patients to the hospital
- d) Upgrade office areas in different parts of the hospital to accommodate newly appointed nursing personnel to the department.

Whilst there will be some ongoing disruption during the building process the long-term aim will be to have excellent facilities for patients and ideal working conditions for all staff.

## Medical Staff

### Introduction

The Oncology/Haematology service is supported by two medical teams, one looking after the solid tumours (Oncology Team) and the other looking after the Haematology disorders, both malignant and benign (Haematology Team). In combination with the nursing staff and allied professional staff the whole unit works together as one large multi-disciplinary team to support all our families. The teams are contactable 24-7 via the hospital switch at 01.4096100 to deal with queries and concerns from patients, their parents and our Shared Care hospitals.

### Oncology Team

The Oncology Team is lead by Dr. Fin Breatnach and Dr. Anne O'Meara. Their non-consultant staff consists of Registrars and Senior House Officers who do six monthly rotations as part of their on-going medical training.

### Haematology Team

The Haematology Team is lead by Prof. Owen Smith, Dr. Aengus O'Marcaigh and Dr. Corrina McMahon. Their non-consultant staff consists of a Specialist Registrar, Registrar and Senior House Officers who do six monthly rotations as part of their on-going medical training.

### Non-consultant hospital doctors (NCHD)

The NCHD's make up the medical support service to the Consultants and are available on a 24 hour rotation to attend to the patient's medical needs. They are changed every six months, in January and July to facilitate their on-going medical education and knowledge.

## **Nursing Staff**

### **Introduction**

The Clinical Nurse Managers act as the co-coordinators in the care of your child. They are primarily responsible for ensuring that your child receives the highest quality of nursing care. The Clinical Nurse Managers wear a green coloured tunic.

All the staff nurses, with the assistance of the student nurses, provide nursing care to meet your child's needs and your needs, while in hospital and at home. The staff nurses wear a light blue coloured tunic, the student's are in white.

Apart from different coloured uniforms all of the nursing staff will wear a name badge which will tell you their name and job title.

### **The IV Team**

The IV team are specially trained nurses who will insert your child's drip when they need one. The cannula (drip needle) is inserted when Hickman Catheters ('Freddie's') are not in place and in certain circumstances i.e. for some tests and procedures.

### **The Clinical Nurse Specialists (CNS)**

There are many types of nurse specialists to help look after the needs of the sick child and their families. The nurse specialists are members of the ward team and they have different roles. Some wear a similar uniform to that of the Clinical Nurse Managers with others wearing 'civvies'.

#### **CNS Parent Educator**

The CNS Parent Educator will teach and educate you within the hospital following your child's diagnosis with cancer. You will be given information about your child's chemotherapy treatment protocol, your child's blood count, what to do at home if your child is unwell and develops a temperature along with many other aspects of your child's care. You will be encouraged to record information in the 'Passport' that you will be given by the nurse specialist once your child is starting treatment. One parent will be asked to care for your child's Hickman catheter at home and learning this procedure will be taught under supervision in the ward.

#### **CNS Liaison Service**

A diagnosis of cancer has a profound effect on patients and their families. To help children and families at this difficult time and throughout their treatment, Our Lady's Hospital for Sick Children has a specific type of hospital based cancer nurse, called a Clinical Nurse Specialist (CNS) who as part of her role will liaise with your GP and local hospital regarding your child's care.

The CNS is not involved in hands-on nursing care; rather they are there to give information and reassurance during the cancer diagnosis and subsequent treatment. The clinical nurse specialists are a valuable channel of communication between the team and their patients, as often patients may be too fearful or overwhelmed to voice a particular worry or concern that they may have.

The CNS is there to provide emotional and practical support and advice to the patient and to their family. These nurses are experienced cancer specialists who contribute to the overall management of a patient, by working as part of the oncology/haematology team and liaising with the family.

Here in the Oncology Unit five Liaison Nurses are working in this service, which provides psychological support to patients in the following major cancer treatment centers.

#### CNS Bone Marrow Transplant Coordinator

This person will educate patients and families regarding Bone Marrow Transplant and will organize all pre-transplant and post-transplant investigation and offer support in the long term follow-up period as well.

#### CNS Haematology

The Haematology CNS looks after the needs of the Leukaemia population within counties Dublin, Kildare & Wicklow and acts as their Liaison Nurse. They are also responsible for those children that have a non-malignant Haematology diagnosis which is not related to coagulation or Haemoglobin disorders. This would include such diagnoses as Anaemia and ITP (Idiopathic Thrombocytopenic Purpura).

#### CNS Haemophilia

There are two Haemophilia CNS's who look after the specialist needs of the children and families diagnosed with any of the Coagulation Disorders. They provide a Monday-Friday service and are supported by the Haematology Medical team and the ward staff.

#### CNS Haemoglobinopathy

The Haemoglobinopathy CNS looks after the specialist needs of those children and their families that have been diagnosed with one of the Haemoglobin Disorders. The most common of these are Sickle Cell Anaemia and Thalassaemia.

# Clinical Nurse Specialist Service

## Introduction

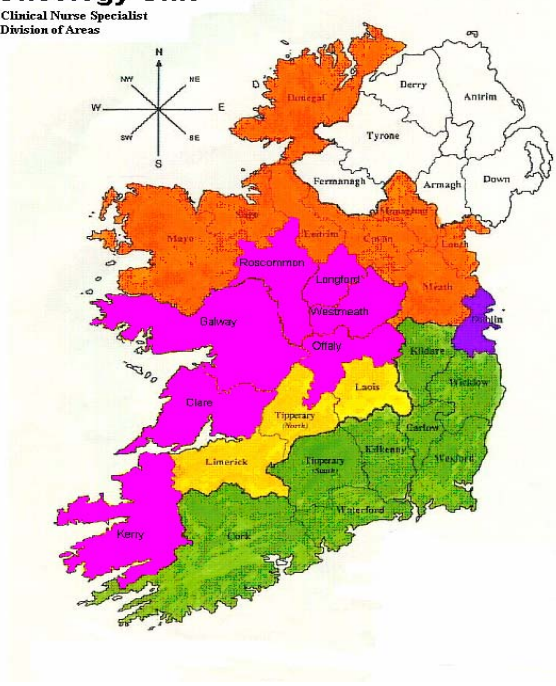
A clinical nurse specialist will meet all children newly diagnosed with cancer, and their families during their stay in hospital. She will act as the link between your child, local hospital, GP, Pharmacy, and treatment centre.

This nurse will arrange a follow up visit shortly after discharge, so that any nursing/medical procedures may be addressed in the home setting. She will continue to work in an advisory and supportive capacity for you and all the professionals involved in your child's care.

All staff has extensive paediatric nursing experience as well as detailed knowledge of hospital and community services. They are available to assist with discharge planning and will work with the multidisciplinary team to develop an appropriate package of home support.

Here in Our Lady's Hospital for Sick Children five clinical nurse specialists support the unit on a regional basis as outlined in the map below.

### Haematology Oncology Unit Clinical Nurse Specialist Division of Areas



#### Services Offered:

- ☛ Link between Hospital, GP, Pharmacy and treatment centre.
- ☛ Issues associated with the home setting
- ☛ Advisory and supportive capacity
- ☛ Palliative care

## Shared Care Centres

### Waterford Regional Hospital

Address: Dunmore Road,  
Waterford.

Consultant: Dr. Paul McMahon  
Dr. John Carson  
Dr. Norma Goggin

Tel: 051 - 842359 (SD 5046)  
Fax No: 051 848564

### Wexford General Hospital

Address: St Gabriel's Ward,  
Wexford General Hospital,  
Wexford.

Consultants: Dr. Anne Sheehan  
Dr. John Carson

Tel: 053 - 53113 (SD 5047)  
Fax: 053 - 53220

### St. Luke's Hospital

Address: Paediatric unit,  
St. Lukes Hosp.,  
Kilkenny.

Consultants: Dr. Clodagh O'Reilly  
Dr. Michelle Dillon

Tel: 056 - 7785266 (SD 5737)

### The Mercy Hospital

Address: Grenville Place  
Cork.

Consultants: Prof Peter Kearney  
Dr. David Coughlan  
Dr. Deirdre Rafferty  
Dr. Olivia O'Mahoney

Tel: 021-4 271971 Ext: 5291 (SD 5035)  
Fax: 021 - 2305005

### Clonmel General Hospital

Address: St Joseph's Hospital,  
Clonmel,  
Co. Tipperary.

Consultant: Dr. I Shana  
Dr. E. McGrath  
Dr. Ilyas Khan

Tel: 052-77090 (SD 5736)  
Fax: 052 -23975

### Letterkenny General Hospital

Address: Letterkenny,  
Co. Donegal

Consultants: Dr. Seamus McGuire,  
Dr. Catherine Ryan  
Dr. Sami El Kashif

Tel: 074 - 23556 (SD 5031)  
Fax: 074 - 23634

### **Sligo General Hospital**

Address: The Mall,  
Sligo.

Tel: 071 - 9174634 (SD 5039)

Consultants: Dr. John Gleeson  
Dr. Hilary Greaney  
Dr. Fuad Khan

### **Mayo General Hospital**

Address: Castlebar,  
Co. Mayo.

Tel: 094 – 9042420 (SD 5025)

Consultants: Dr. Gay Fox  
Dr. Michael O’Neill,  
Dr. El – Abbass

### **Mullingar General Hospital**

Address: Mullingar,  
Co. Westmeath.

Tel: 044 - 39160 (SD 5036)  
Fax: 044 - 43155

Consultants: Dr. Terry Bate  
Dr. Imelda Lambert –job shares with  
Dr. Geraldine Prendiville

### **Cavan General Hospital**

Address: Cavan

Tel: 049 - 4376616 (SD 5026)  
Fax: 049 - 4361065

Consultants: Dr. Alan Finan  
Dr. Anne Leahy  
Dr. Nick Van Der Speek

### **Our Lady of Lourdes Hospital**

Address: Drogheda,  
Co. Louth.

Tel: 041- 9874679 (SD 5727)  
Fax: 041 - 9874725

Consultants: Dr. Siobhan Gormally  
Dr. Alf Nicholson,  
Dr. Matthew Thomas,  
Dr. Brian Mulhern,  
Dr. David Vaughan.

### **Portiuncula Hospital**

Address: Ballinasloe,  
Co. Galway.

Tel: 0905 – 42898/6 (SD 5038)  
Fax: 0905 42916

Consultants: Dr. Kevin Connolly,  
Dr. Mohamed El Tayeb  
Dr. M. Parameshwar

### **University College Hospital**

Address: Newcastle Road,  
Galway.

Tel: 091- 544271/2 (SD 5045)  
Fax: 091 - 581804

Consultant: Dr. Kevin Dunne  
Prof. Gerry Loftus, Dr. David Lyllis  
Dr. M. Murray, (Haematologist)  
Dr. Maccon Keane (Oncologist)

### **Limerick Regional Hospital**

Address: Dooradoyle,  
Limerick.

Consultant: Dr. Liam Carroll  
Dr. Stack,  
Dr. Michael Mahoney  
Dr. Con Sreenan  
Dr. Roy Philip

Children's Ward (Sunshine Ward)  
Tel: 061- 482280/1 (SD 5032)  
Paediatric Day Unit (Caterpillar Ward)  
Tel: 061 - 482706  
Fax: 061 - 482434

### **Portlaoise General Hospital**

Address: Portlaoise,  
Co. Laois.

Consultants: Dr. Matt Conran,  
Dr. Geraldine Nolan  
Dr. Hadar Ahmed

Tel: 0502 - 78208 (SD 5726)  
Fax: 0502 22986

### **Tralee General Hospital**

Address: Tralee,  
Co. Kerry.

Consultants: Dr. Bob Fitzsimons,  
Dr. Fergus Leahy

Cashel Ward  
Tel: 066 - 7184360 (SD 5034)  
Fax: 066 - 7124241  
Fax location: Administration

### **Other Linked Hospitals.**

#### **Beaumont Hospital**

Address: Beaumont Road,  
Dublin 9.

Consultant: Mr. David Allcutt  
(Neurosurgeon)

Tel: 8093100 (SD 5001)  
Direct line to St. Gabriel's Ward: 8092502/3050  
Fax: 8376982

#### **St. Luke's Hospital**

Address: Highfield Road,  
Rathgar,  
Dublin 6.

Consultant: Dr. Catriona O' Sullivan

Tel: 4974552 (SD 5696)  
Fax: 4976237

## **Research Nurses**

There are presently two research nurses one for each discipline Haematology/Oncology working in St. John's Ward. They are an important new resource to the multidisciplinary team. They meet with patient/parents with the consultant regarding diagnosis and clinical treatment and they provide written information to the parents/patient to read. They ensure that relevant bloods/investigations are obtained according to the individual trial. They notify any side effects of treatment to the Data Manager for reporting.

## Patient Information on Cancer

### Introduction

Cancer begins when a particular cell or group of cells begin to multiply and grow without control. Eventually, the normal cells will be crowded out and the cancerous cells, if not treated, will take over. Oncology is the study of these cells.

The Paediatric Oncologist/Haematologist specializes in the diagnosis of children's cancers.

Sometimes the cancer will affect the blood, causing Leukaemia. Other cancer cells form Tumours. A tumour is an abnormal lump of tissue formed by a collection of cells. These may be benign or malignant. When these tumours form in bone or muscle they are known as Sarcomas.

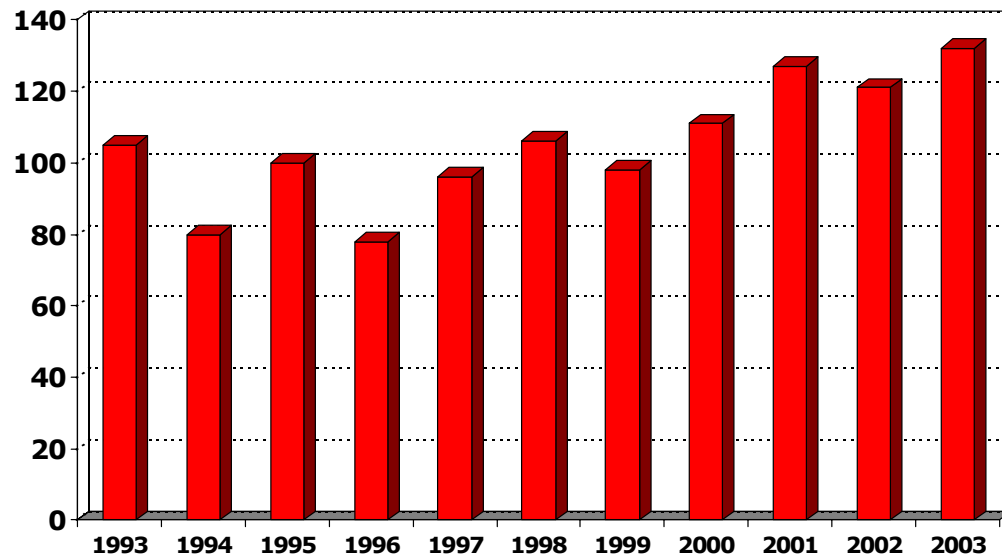
Cancer which affects the lymphoid organs such as the lymph nodes, spleen and thymus are known as Lymphomas.

No one knows what causes childhood cancer. It is reassuring to know, however, that nothing we as parents did or did not do caused our child's cancer.

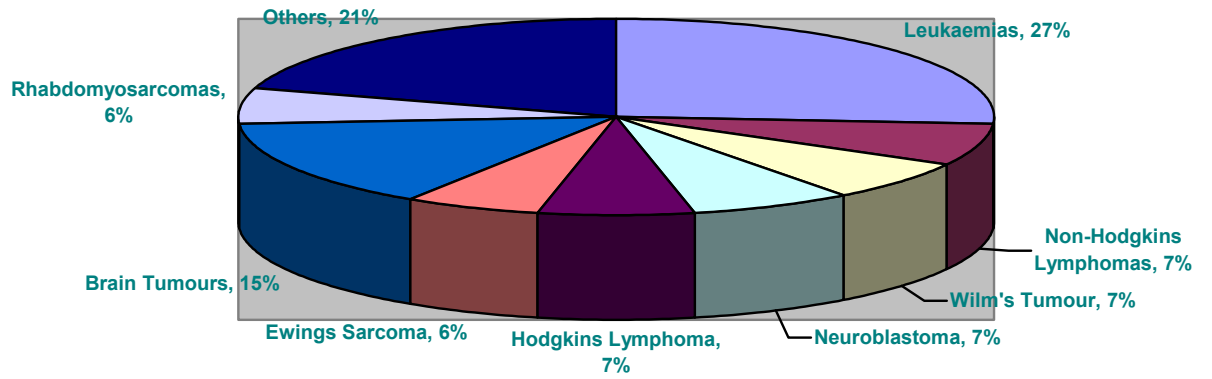
It is not contagious and most children's cancers can be treated very effectively nowadays.

Cancer is treatable, and many cancers are curable. Children who have cancer now live longer and more comfortably than ever before. Since 1957, over 2,600 children with cancer have received treatment at the Unit, and more than 1,600 are survivors, with between 130 and 150 new children being diagnosed with cancer each year. Here in the Oncology & Haematology Unit we take a multi-disciplinary approach, to cancer treatment. We try to understand the needs of cancer children and their families, and seek to provide the highest standards of possible quality of care and services.

### Children Diagnosed with Cancer at OLHSC between 1993 & 2003



## Childhood cancers at OLHSC between 1998 & 2003



## Common Childhood Cancers



### ● Leukaemia

Leukaemias are the most common cancer in children. Acute Lymphoblastic Leukaemia accounts for approximately 27% of all childhood cancers. Children with leukaemia usually develop tiredness and become pale as they develop the disease. Bruising is often a feature. The diagnosis is established through examination of the bone marrow.

Treatment consists of an intensive phase of chemotherapy lasting six or seven months followed by less intensive therapy which last a further year and a half.

The cure rate depends on the particular type of leukaemia and ranges from 50% – 90%.

### ● Lymphomas

Non-Hodgkin's Lymphoma is the most common type of childhood lymphoma and usually presents with enlargement of a group of glands somewhere in the body, perhaps in the neck, chest, or abdomen.

The diagnosis is usually established as a result of biopsy of one of the affected glands.

Treatment usually consists of chemotherapy, which last between six months and two years, and may include surgery or radiotherapy.

Cure rates depend on the extent and type of lymphoma and range between 60% - 100%

Hodgkin's disease is a rarer type of childhood lymphoma and presents in the same way as Non-Hodgkin's Lymphoma. If the disease is localised then radiotherapy alone is used.

If the disease is more wide-spread then chemotherapy, lasting six to eight months is common. Rates of cure range between 60% - 100%.

### ● Wilm's Tumour

Wilm's Tumour (Nephroblastoma) is a tumour affecting the kidney and affects approximately seven children in Ireland every year.

Symptoms are usually non-specific and parents frequently become suspicious when they notice that the tummy becomes extended or feels particularly firm.

The diagnosis is usually established through a biopsy of the tumour or through its initial removal. Treatment always involves surgery at some stage and chemotherapy. Radiotherapy is used for advanced disease. Rates of cure are extremely high and average over 85% at the hospital.

### ● Neuroblastoma

Neuroblastoma occurs in approximately seven children in Ireland every year. The tumour arises from a special part of the nervous system. In two thirds of cases, the tumour arises within the abdomen. Quite frequently children with this tumour have disease in many parts of the body by the time they develop symptoms.

The diagnosis is established through a biopsy and through urine tests. Treatment consists of chemotherapy, surgery, and occasionally radiotherapy. Bone marrow transplant is occasionally required. In its advanced state this tumour is quite difficult to cure. Rates of cure range from 40%- 100% depending on type and extent of disease.

### ● Bone Tumours

The most common malignant tumours arising in the bones are Ewing's Sarcoma and Osteosarcoma. These tumours affect three to four children per year. Symptoms most frequently reported are of pain and occasionally swelling of the affected bone.

The diagnosis is established following a biopsy and the treatment always includes chemotherapy. Surgery has a major part to play in the treatment of some tumours whilst radiotherapy is an essential part of treatment for others.

Rates of cure depend on the original site of the tumour and its extent throughout the body  
And range between 50%-80%.

### ● Brain Tumours

There are many different forms of brain tumour, some benign, others malignant. They account for about 20% of all childhood cancers. Brain tumours do not usually spread throughout the body. The most common are those of headache, vomiting and drowsiness.

These symptoms are a result of increased pressure within the skull. The diagnosis is usually established following a CT or MRI scan of the brain. Treatment consists of surgery often followed by radiotherapy and/or chemotherapy. Cure rates vary depending on the type of tumour.

### ● Rhabdomyosarcoma

Several slightly different types of tumour may grow in muscles or sinews or the fibrous tissues that surround muscles. The most common is Rhabdomyosarcoma.

The tumour most commonly develops in children between birth and five years of age.

The tumour may appear in the head or neck, including the muscles around the eyes, in the back of the throat, in the cheek or in part of the ear inside the skull. Other parts of the body often affected include the bladder, womb, vagina, prostate, and the muscles near the testis. Less commonly, the tumour grows in the muscles of the arms or legs.

Approximately ten children in Ireland develop this cancer every year. The diagnosis is always established following a biopsy of the lump.

Treatment consists of surgery where possible, chemotherapy and, if necessary radiotherapy. Treatment may last from five to twelve months. Rates of cure depend of the type and extent of the tumour but average 65%.

### • Other Tumours

There are many extremely rare tumours, which can arise in children. Liver tumours and nasopharyngeal tumours are two such examples with no more than one child per year developing either of these.

The main symptom of the liver tumour is pain in the abdomen, weight loss, and jaundice. A C.T. scan is often performed and the diagnosis may be established through a blood tests and biopsy of the tumour. Chemotherapy is usually used and surgery removal of the tumour is often considered necessary.

Cure rates are extremely high when the tumour is removed. In the vent that the tumour cannot be removed the addition of radiotherapy may result in a cure.

Nasopharyngeal tumours appear in an area above the roof of the mouth called the nasopharynx. They may discharge from the ear or bleeding from the nose. Sometimes the first sign of this tumour is a swollen gland at the side of the neck. A biopsy of the tumour or gland is necessary to confirm the diagnosis and a C.T. scan will demonstrate its extent. It is not usually necessary to remove these tumours surgically and treatment is with chemotherapy and radiotherapy. Cure rates continue to improve.

Other forms of childhood cancers include:

### • Germ Cell Tumours

Germ Cells are the cells that become the embryo which develops into a child in the womb. Some of these cells remain in different parts of a child's body after birth and may produce tumours. These tumours may be benign or malignant. They are very rare with only one or two children each year being affected. Symptoms vary depending on where the tumour is but usually a lump appears or can be felt.

The diagnosis may be established through a special blood test but more often a biopsy is necessary. Treatment of malignant tumours requires chemotherapy and surgery. Radiotherapy may also be necessary.

The cure rate is extremely high and approaches 100%.

### ● Histiocytosis

Langerhan's Cell Histiocytosis is a rare disease but not a malignancy, with no more than one child in Ireland developing this disease each year. Children are very young with most been under two years of age. A histiocyte is a normal cell found in many parts of the body. In the disease the cells increase in number and affect many parts of the body symptoms are usually more specific.

The cause is unknown but it is not inherited, infectious or cancerous. Treatment varies depending on the extent and location of the disease and may involve surgery, mild chemotherapy or careful observation only. The outcome is very good with over 80% of children being cured.

### ● Retinoblastoma

Retinoblastoma is a malignant tumour, which arises at the back of the eye. It develops in the cells of the retina, the light-sensitive lining of the eye. Only one or two children develop this tumour every year. Children are very young when they develop this tumour with most being under two years of age. In some cases only one eye is affected.

However, nearly 40% of children have the tumour in both eyes. The tumour may develop in the second eye some weeks or months after the original diagnosis. Heredity plays a part for some children.

The usual presenting symptoms are as squint or an abnormal appearance of a pupil. The diagnosis is usually established through examination of the eyes.

Treatment depends on the size, position and number of tumours. Small tumours may be treated using a laser beam or by freezing. Slightly larger tumours are treated with local radiotherapy. For very large tumours removal of the affected eye is, unfortunately, sometimes necessary. Chemotherapy is given when the tumour has spread beyond the eye. Cure rates are very high and exceed 90%.

## **Cancer Information & Support Services for Families**

Irish Cancer Society (Link)

[www.cancer.ie](http://www.cancer.ie)

National Cancer Registry of Ireland (Link)

[www.ncri.ie](http://www.ncri.ie)

Department of Health (Link)

[www.doh.ie](http://www.doh.ie)

Irish Clinical Oncology Research Group (Link)

[www.icorg.ie](http://www.icorg.ie)

United Kingdom Children's Cancer Study Group (Link)

[www.ukccsg.org](http://www.ukccsg.org)

European Cancer Leagues (Link)

[www.uicc.org](http://www.uicc.org)

American Cancer Society (Link)

[www.cancer.org](http://www.cancer.org)

Barretstown (Link)

[www.barretstown.org](http://www.barretstown.org)

Cancer BACUP (Link)

[www.cancerbacup.org.uk](http://www.cancerbacup.org.uk)

Cancer & Leukaemia in Children (Link)

[www.clc.org.uk/aboutus/aboutus.php](http://www.clc.org.uk/aboutus/aboutus.php)

Malcolm Sargent (Link)

[www.malcolmsargent.org.au](http://www.malcolmsargent.org.au)

Children's Cancer Web (Link)

<http://www.cancerindex.org/ccw/>

Great Ormond Street Hospital (Link)

<http://www.ich.ucl.ac.uk/>

## Patient Information about Haemophilia

Our Haemophilia Centre provides multidisciplinary comprehensive care for children and adolescents with inherited bleeding disorders. Services include diagnosis, acute and chronic medical management of haemophilia and its complications, genetic counselling, physical therapy, counselling and coordination with other services. Patient/family education, home infusion programs, assessment and treatment of bleeding episodes, counselling and community education family support are important components of this program. These patients have contact with the Haemophilia CNS.

### Links:

Haemophilia Ireland Website [www.ihs.ie/](http://www.ihs.ie/)

U.K. Haemophilia Society [www.haemophilia.org.uk](http://www.haemophilia.org.uk)

World Federation Haemophilia Website [www.wfh.org](http://www.wfh.org)

## Patient Information about Haemoglobinopathies

### Definition

Haemoglobinopathies are genetic (inherited) disorders of haemoglobin, the oxygen-carrying protein of the red blood cells. These patients have contact with the Haemoglobinopathy CNS.

### Thalassemia

The fundamental abnormality in thalassaemia is impaired production of either the alpha or beta haemoglobin chain. Thalassaemia is a difficult subject to explain, since the condition is not a single disorder, but a group of defects with similar clinical effects.

### Links:

Great Ormond Street Hospital Website- search under anaemia's @

<http://www.ich.ucl.ac.uk/>

### Sickle Cell Disease

Our Sickle Cell patients are cared for under the direction of Dr. Corrina Mc Mahon, one of the Haematology Consultants. They also have their own CNS Haemoglobinopathy. The hospital looks after the national needs of those with Sickle Cell Disease. We provide medical care and support services for children with sickle cell disease.

### Links:

Great Ormond Street Hospital Website- search under anaemia's @

<http://www.ich.ucl.ac.uk/>

## Patient Information about the Anaemia's

### What is anaemia?

Anaemia is a condition where the number of red blood cells or the amount of haemoglobin in red blood cells is less than normal.

Red blood cells contain haemoglobin. This is the substance that makes blood red. Its main purpose is to carry oxygen around the body. If the body cannot receive enough oxygen, various symptoms occur. These include fatigue, weakness and lack of energy. If the anaemia becomes more severe, it can become life threatening.

Anaemia can be caused by many things, including losing a lot of blood after surgery or an accident, a decrease in the number of red cells being produced in the bone marrow, or an increase in the number of red cells being destroyed by the body.

These patients have contact with the Haematology CNS.

### Links:

Great Ormond Street Hospital Website- search under anaemia's at

<http://www.ich.ucl.ac.uk/>

## Barretstown – Magic for Families



### Introduction

The Barretstown Gang was founded by Paul Newman in 1994, after the success of his Hole in the Wall Gang Camp in the USA. He started the charity with \$2 million of his own money and Barretstown Castle, which was kindly donated by the Irish Government. Thanks to many generous companies and individuals, we have turned it into a first class facility for seriously ill children.

Barretstown has already welcomed thousands of these children as well as the members of their families, who have also been deeply affected. This wouldn't have been possible without the €30 million in donations that has helped us to create and maintain our unique centre.

Our 2004 season of programmes will welcome over 1,500 seriously ill children and family members from Ireland, Britain and throughout Europe.

Our long-term vision is to construct additional facilities to eventually reach full capacity, serving up to 2,000 children and family members each year.

When Barretstown celebrates its 10<sup>th</sup> anniversary in 2004 it can also justly celebrate having welcomed almost 400 families to Barretstown since our family programme began in 1996.

The family programme was designed to offer the family of a seriously ill child respite from some of the stresses of living with a life-threatening illness. For up to four weekends each spring and autumn as many as fifteen families come to Barretstown from all over Ireland and elsewhere to experience what many parents have described as the 'magic' of Barretstown.

The family programme has been an outstanding success and has had many families from St Johns Ward at OLHSC.

