



CHILDHOOD CANCER

ALCCRF

Australian Lions Childhood Cancer Research Foundation

a

Service Opportunity



Global Cause Childhood Cancer





GLOBAL CAUSE - CHILDHOOD CANCER

- Why Childhood Cancer.
- From an LCI Brochure
 - No child deserves cancer. Yet lymphomas, leukemias, and other forms of the disease common in children are the stark reality for many youth and their families in all parts of the world. There is both heartache and hope.



GLOBAL CAUSE - CHILDHOOD CANCER

- Cancer is a leading cause of death for children and adolescents around the world.
- Approximately 300,000 children are diagnosed with cancer each year.
- Childhood cancer generally cannot be prevented or screened.
- Only 20% of countries have early detection guidelines and only 33% have a defined referral system for medical resources.



GLOBAL CAUSE - CHILDHOOD CANCER

WE HAVE A PLAN

- Increase acts of support to families and children affected by childhood cancer.
- Improve diagnostics, treatment, and continued care to those affected by childhood cancer.
- Increase awareness for childhood cancer as a global priority.



LCIF CHILDHOOD CANCER FOCUS GROUP

Focus Groups - Constitutional Area 7

2020 Teleconference

- **Australia**
- **New Zealand**
- **Indonesia**
- **New Caledonia**



NEW ZEALAND

Top cancer diagnoses in New Zealand (*last decade stat*)

- ❖ Leukaemia (1/3 of all cases)
- ❖ Central nervous system tumours (21% of all cases)

Lions Involvement

- Work with cancer charities in our local communities.
 - Support Canteen.
 - Support Camp Quality.
- Continue to bring hope through tangible service and support.



INDONESIA

- New cases of childhood cancer (last decade stat) - 4,100.
- Number of oncologists specialising in childhood cancer - 70.



NEW CALEDONIA

- "The bell to ring" July 2021 for children cured of a childhood cancer.
- Lions Sport Action Association raises funds through sports.
- Golf proceeds go to France for research.



ALCCRF - THE RELATIONSHIP WITH LCIF



Lions Clubs International
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Auckland ANZI Pacific Forum 2015

International President Dr Yamada meeting with Prof John Maddick - Garvin Institute.

Prof Maddick - Saturday lunchtime speaker introducing the Genome sequencing project that was to become the Lions Kids Genome Project.



ALCCRF - THE RELATIONSHIP WITH LCIF

Lions Kids Cancer Genome Program

ALCCRF initiated a campaign in 2015 which was announced at the 2016 National Convention to commence the world's first Genome Sequencing Project for Kids with high-risk cancers.

- ALCCRF Genome Sequencing initiative
- \$4.0 million dollar funding project
- \$1.3 million provided by the Lions of Australia via ALCCRF
- \$2.7 million provided by LCIF



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"Every child
deserves a chance
at a healthy life"

"Our little Star Of Hope"



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Australian Lions Childhood Cancer Research Foundation (ALCCRF)

- Endorsed by Delegates at the 2009 MD Convention in Melbourne.
- Trust Deed to underpin the Foundations establishment and operation.
- First Meeting of Trustees held in July 2010.
- Chairperson and 5 Trustees.
- Expanded to a Chairperson and 9 Trustees, all States 2012.



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Our Problem

- Each Year around 1,000 kids are diagnosed with Cancer in Australia
- Sadly 150 of these will die, That's an average of 3 each Week
- Most of the survivors experience severe, often lifelong side effects of therapy



"Every child deserves a chance at a healthy life"





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Our Vision



"100% Survival for Kids with Cancer"



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Our Mission

"Prevent Kids with Cancer dying by raising funds nationally and donating those funds to the best high impact childhood cancer research conducted right across Australia"



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Why Focus Lions Support on Research

Trustees entered a partnership with Macquarie (University) Graduate School of Management (MGSM) - Donors Without Borders publication.

The report from MGSM, released in late 2014, was also made available to other philanthropic groups, universities and government.

ALL submissions for research funding are measured against a report to determine if it meets the priority for funding.



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Research Fundraising

Donations.

- By Cheque or Direct Deposit.

Lions Biggest BBQ.

- Annually January - December, when it best suits your Club.
- Can be any fundraising event doesn't have to be a BBQ.

Awards.

- ALCCRF Bronze \$250, Silver \$500, Gold \$1,000.
- Barry J Palmer Fellow \$2,000.



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Research Fundraising

Merchandise.

- BBQ Aprons \$20, Pens \$5, Christmas Pins \$6.

Lions Rose

- Refer website, available from Treloar Roses, ALCCRF receives \$1 for every rose sold (currently \$23.95).

Coin Line

- Initiative of the Elermore Vale Lions Club & District N3 Clubs
- Guinness World Record for the longest coin line attempt 85 km.



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Snapshot of Early Projects of ALCCRF

2011 Funded the first ever national 'Phase 2' Neuroblastoma clinical trial.

- Donated \$100,000 then immediately set out to raise a further \$200,000 which we did with the help of Lions clubs across Australia in less than 12 months to enable the trial to be completed.



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Snapshot of Early Projects of ALCCRF

2012 ALCCRF agreed to become a funding partner with the Royal Children's Hospital Melbourne (RCH).

- *Committed \$120,000 per annum for 3 years to fund the 'Head Researcher of Solid Tumours' research position.*



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Snapshot of Early Projects of ALCCRF

2013 ALCCRF formed an amazing relationship with Ava Bell who has become an ALCCRF ambassador and our "Little Start of Hope":

- *6 months old woke up struggling to breath - had a 5½ centimetre cancerous tumour called a neuroblastoma in her chest and abdomen.*



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Snapshot of Early Projects of ALCCRF

Supporting a Senior Biobank Specialist for the Hudson/Monash Paediatric Precision Medicine Program and Genomic Annotation of Rare Childhood Solid Tumours.

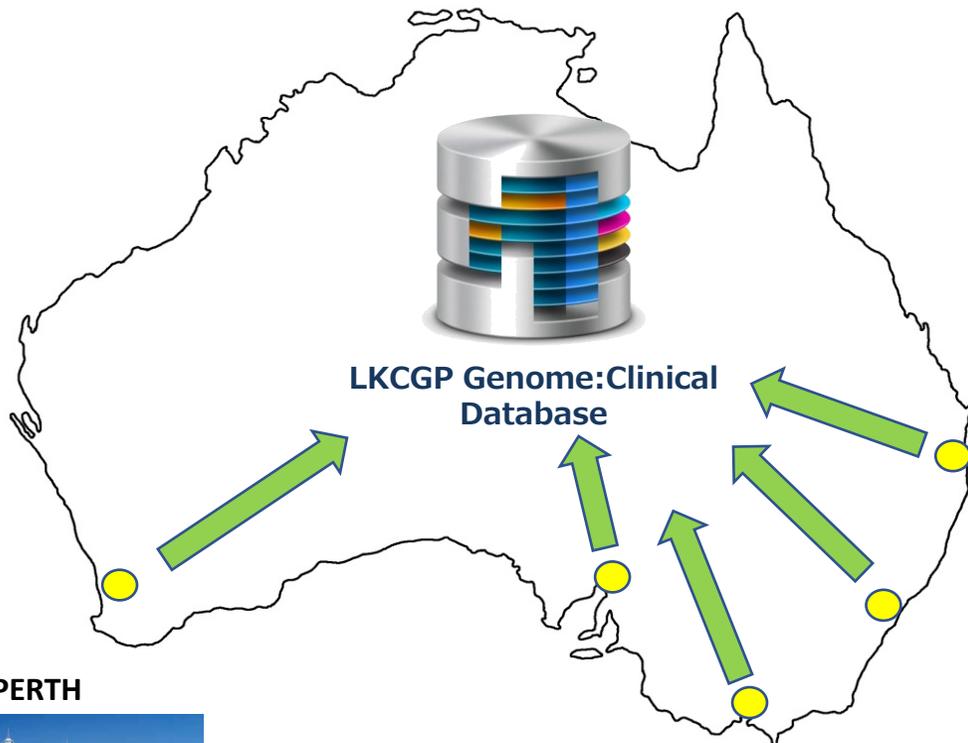
Funding Cost: \$450,000 over 3 years commencing September 2019.

Snapshot of Early Projects of ALCCRF

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LKCGP Genome: Clinical Database

BRISBANE



Lady Cilento Children's Hospital

SYDNEY



Sydney Children's Hospital

- Randwick
- Westmead
- John Hunter Children's Hospital (Newcastle)

PERTH



Princess Margaret Hospital

ADELAIDE



Women and Children's Hospital

MELBOURNE



Royal Children's Hospital
Monash Children's Hospital

Lions Kids Cancer Genome Project



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Research Currently Funded

Cancer Australia (Federal Govt. Dept. of Health) co-funding solid tumour research on \$ for \$ basis with other partners

- **Dr Pouya Faridi:** Monash University Novel targets for paediatric brain tumour immunotherapy. Our share of Funding Cost: \$66.6k, 3 years commencing June 2021.
- **Dr Jessica Buck:** Telethon Kids Institute Exploiting and enhancing brain-resident immune cells for the treatment of paediatric brain stem glioma (DIPG). Our share of Funding Cost: \$49.8k, 3 years commencing June 2021.



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Research Currently Funded



- **Dr Andrew Care: University of Technology Sydney - Engineering a protein nanocage for targeted ionophoric-copper therapy. Our share of Funding Cost: \$63.9k, 3 years commencing March 2020.**
- **Telethon Kids Institute - Paediatric Immunotherapy Program for high-risk kids with cancer. Funding Cost; \$1.05 million over 3 years commencing January 2020.**

Video to follow shortly





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Research Currently Funded



- **WEHI (Walter & Eliza Hall Institute) - Tackling drug treatment resistance to medulloblastoma** discovering how cells that are tolerant to existing therapies survive treatment and become resistant to treatment.
- **Funding Cost: \$220,000 over 2 years commencing January 2022.**
- **Griffith University's, Institute for Glycomics - Focus on Sarcoma** early markers, improve diagnosis targeting pathways to treatment.
- **Funding Cost: \$800,000 over 3 years commencing January 2022.**





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Keeping In Touch With ALCCRF

- Quarterly Newsletter.
- Liaise with District Chairperson.
- Multiple District & District Conventions.
- ANZI Pacific Forums (MD201).
- Invite District Chair / Trustee to speak at club meeting.
- Website - <https://alccrf.lions.org.au/>
- www.lionsclubs.org.au/alccrf



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"Every child deserves a chance at a healthy life"



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We Need Your Help!



SOME OTHER INITIATIVES WORLD WIDE

GLOBAL HOPE

- Global HOPE is focused on systematically curbing death among children with cancer in sub-Saharan Africa.
- It is program that is U.S. based. Partnering with Global HOPE are Lions Clubs International Foundation (LCIF) and Lions.
- Global HOPE supports access to cancer care centres for thousands of children in Botswana, Malawi, and Uganda.



SOME OTHER INITIATIVES WORLD WIDE

- Cans for Kids - Marquette Lions, Michigan USA.
- Lions in Paraguay adopt a children's hospital - the only facility in Paraguay fully dedicated to treating children.
- Lions in Bosnia and Herzegovina with assistance from LCIF establish the country's first mobile follow-up program for families previously left on their own.

Check out our digital Lion Magazine at the LCI website for stories of Lions Club helping in this Global Cause.



Childhood Cancer Grant Program



Lions Clubs International
FOUNDATION

- Grants are available to Lions Districts and Multiple Districts in amounts from US\$10,000 to US\$150,000.
- Projects must be implemented in coordination or collaboration with existing government or charitable childhood cancer medical facilities.
- The Childhood Cancer grant program will not fund medical care directly. If an applicant wishes to implement a project involving medical equipment or infrastructure, they may be eligible to apply for support through the LCIF Matching grant program



Childhood Cancer Grant Program



Lions Clubs International
FOUNDATION

Project examples include but are not limited to:

- Construction, expansion, or renovation of child, teenager, and family-friendly waiting rooms in healthcare facilities.
- Construction, expansion, or renovation of rooms or houses where families can rest, sleep, or cook meals while their child is receiving treatment.
- Projects that strengthen access to or improve transportation to and from medical appointments.
- Projects that address the educational and recreational needs of childhood cancer patients receiving treatment at a healthcare facility.
- Infrastructure to support palliative care.



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Different Types of Childhood Cancer

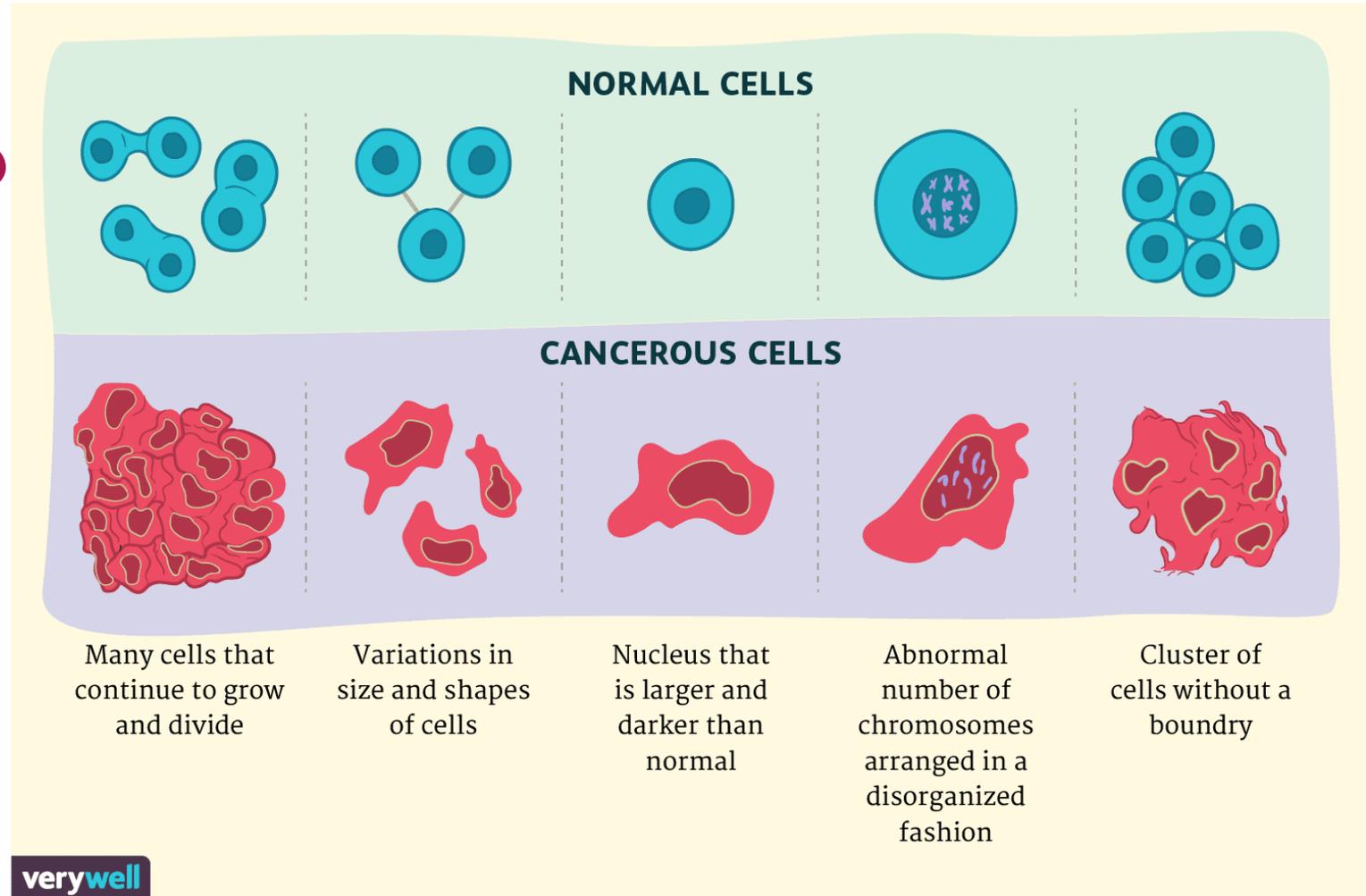


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What is Cancer?

Cancer is a cell growth disease.





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The Statistics

- 1,000 children diagnosed in Australia each year (0-14 yrs).
- Leukemia accounts for 33%.
- 25% are tumors of the central nervous system.
- 10% are Lymphomas.
- 48% of these 1,000 cases are children aged 0-4 yrs.
- Australia has the 5th highest childhood cancer rates in the G20.
- The rates of childhood cancer has risen by 35% since 1983.





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The Prognosis

- 101 children under 15 years old die each year.
- 39% due to central nervous cancer.
- 22% due to Leukemia.
- 13% due to Neuroblastomas.





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Survival

- 1-3% will develop a new childhood cancer.
- Twice as likely to develop a second cancer after 40.
- Long term affects of the treatment.

These include:-

- Heart and lung problems.
- Growth and development problems.
- Learning difficulties.
- Sexual health and fertility.





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Types of Childhood Cancer

- Leukemia
- Brain and spinal cord tumors
- Neuroblastoma
- Wilms tumor
- Lymphoma (including both Hodgkin and non-Hodgkin)
- Rhabdomyosarcoma
- Retinoblastoma
- Bone cancer (including osteosarcoma and Ewing sarcoma)



Childhood Cancer Awareness



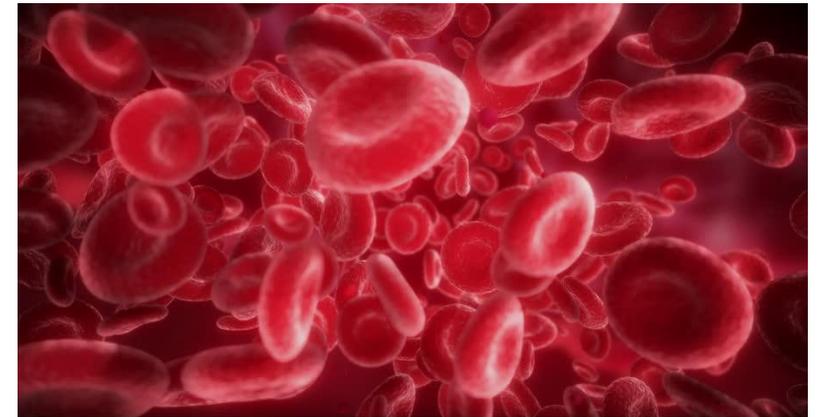
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Leukemia

- Most common cancer in children.
- 28% of all childhood cancer.
- Is a cancer of the bone marrow and blood.
- Why is bone marrow important.
- Symptoms- bone and joint pain, fatigue, weakness, pale skin, bleeding or bruising, fever, weight loss, and other symptoms.
- Acute leukemia's can grow quickly, so they need to be treated (typically with chemotherapy) as soon as they are found.





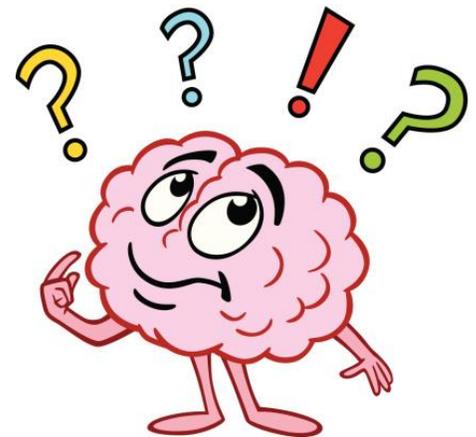
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Brain and Spinal Cord Cancers

- Second most common childhood cancer.
- Accounts for 26%.
- Lower parts of the brain, such as the cerebellum or brain stem.
- Symptoms :- headaches, nausea, blurred or vomiting, double vision, dizziness, seizures, trouble walking or handling objects, and other symptoms.
- Spinal cord tumors are less common than brain tumors in both children and adults.





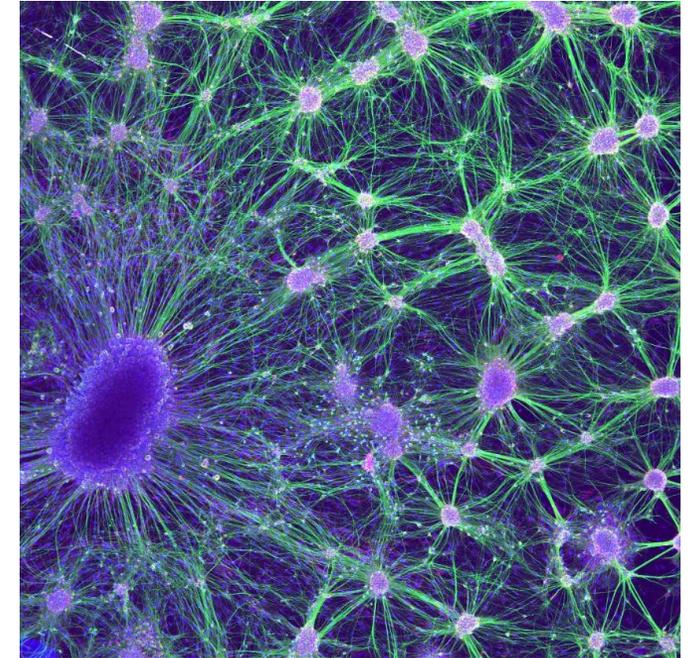
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Neuroblastoma

- Neuroblastoma starts in early forms of nerve cells.
- Approximately 6%.
- This type of cancer develops in infants and young children.
- The tumor can start anywhere.
- It can also cause other symptoms, like bone pain and fever.





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Wilms Tumor

- Starts in one, or rarely, both kidneys.
- 5% of childhood cancers.
- Effects mostly 3 to 4 years old.
- It can show up as a swelling or a lump in the belly.
- Symptoms:- fever, pain, nausea, or poor appetite.





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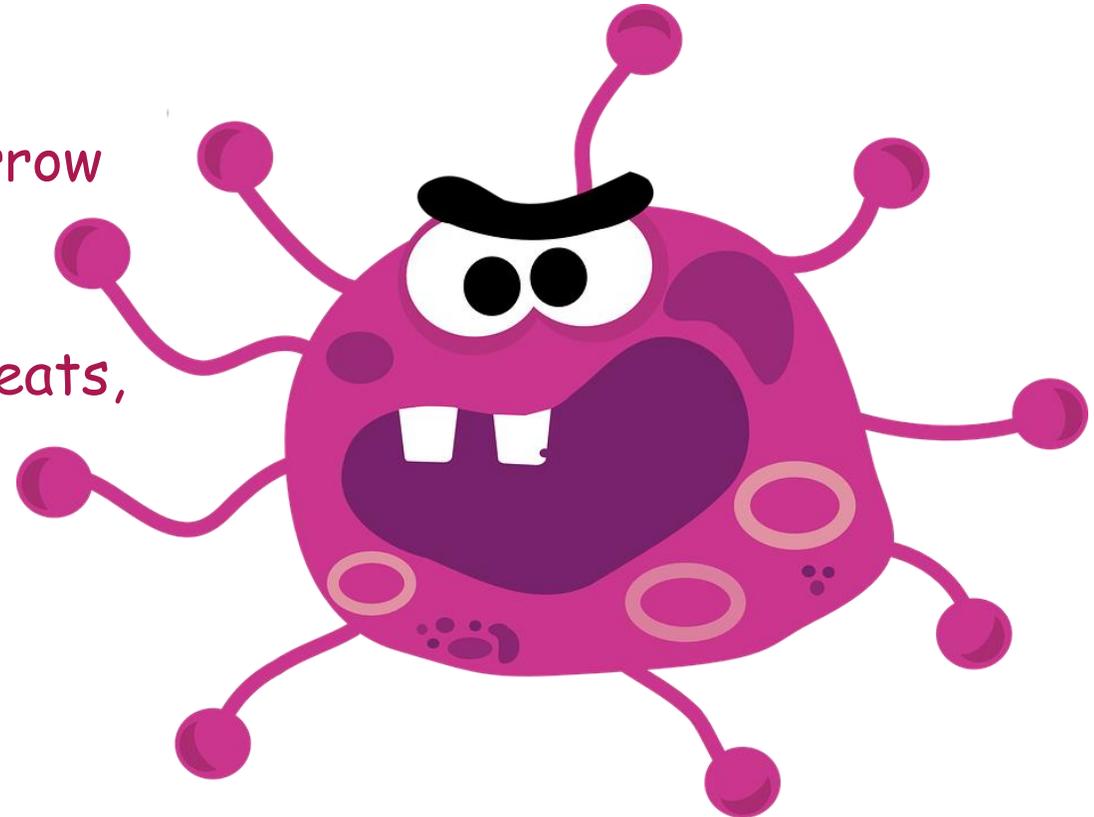


Lymphomas

- Start in immune system cells called *lymphocytes*.
- They can also affect the bone marrow and other organs.
- Symptoms :-weight loss, fever, sweats, tiredness (fatigue), and lumps.

The 2 main types of lymphoma

- Hodgkin lymphoma.
- Non-Hodgkin lymphoma.





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Rhabdomyosarcoma

- Rhabdomyosarcoma starts in cells that normally develop into skeletal muscles.
- Can start nearly any place in the body, including the head and neck, groin, belly (abdomen), pelvis, or in an arm or leg.
- Symptoms:- pain, swelling (a lump), or both.
- Most common type of soft tissue sarcoma in children.
- It makes up about 3% of childhood cancers.





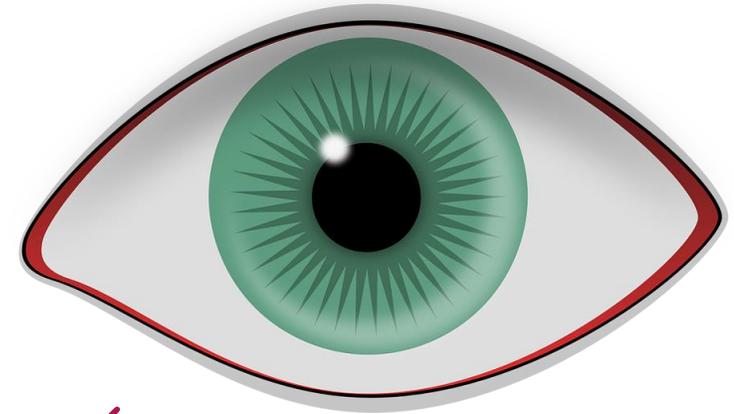
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Retinoblastoma

- Retinoblastoma is a cancer of the eye.
- It accounts for about 2% of childhood cancers.
- Occurs in children around the age of 2, and is seldom found in children older than 6.
- Retinoblastomas are usually found because a parent or doctor notices a child's eye looks unusual.
- In an eye with retinoblastoma, the pupil often looks white or pink.





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Bone Cancers

- Cancers that start in the bones (primary bone cancers).
- occur most often in older children and teens.
- They account for about 3% of childhood cancers.

Two main types - Osteosarcoma, is most common in teens.



- Symptoms- bone pain that gets worse at night or with activity.
- Swelling in the area around the bone.
- **Ewing Sarcoma**, is a less common type of bone cancer.
 - It is most often found in young teens.
 - Symptoms can include bone pain and swelling.



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The Good News

- Childhood death rates have decreased by 3% every year.
- The 5 year survival rate has increased.
- Australia has the lowest mortality rate of all the G20 Countries.
- Genome project - the government now pays for genome testing, which can only lead to a higher survival rate.
- ALCCRF Telethon Kids Immunotherapy Project has the ability to boost children's own immunity to fight off the cancer. This will lead to higher survival rates but more importantly less long term side effects.