Patient and Public Newsletter

Funded by: CANCER RESEARCH UK for Children & Young People; Blood cancer UK

VIVO BIOBANK NEWSLETTER - CHILDHOOD CANCER AWARENESS MONTH

Welcome to Our Special Edition Newsletter for Childhood Cancer Awareness Month.

In this issue, we celebrate how samples generously donated to VIVO Biobank are helping to support childhood cancer research. We look back at the **Children's Cancer and Leukaemia Group (CCLG) Annual Conference in Manchester**, where PPIE and researcher perspectives explored the importance of donated tissue, and share recent VIVO-supported research in leukaemia and neuroblastoma.

We also explore the importance of **diversity in PPIE** and why hearing from a wide range of experiences and perspectives matters. Our three-part **PPIE-led video series** (page 4), is a great example of this collaboration. Created with valuable contributions from our PPIE members, the videos help patients and families understand biobanking, address common concerns, and hear first-hand experiences of biobanking and working with VIVO Biobank.

Thank you everyone for giving their time, experience and support to VIVO Biobank. **Your involvement helps us continue to shape VIVO around the people and communities it is here to support.**

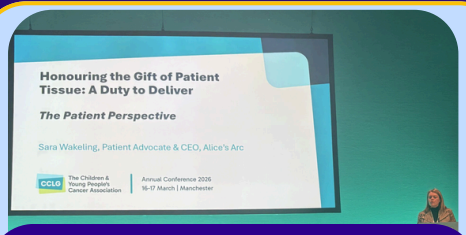
VIVO Biobank Research Highlights
at the CCLG Annual Conference 2026

CCLG The Children & Young People's Cancer Association

This year, VIVO Biobank organised a dedicated R**esearch Highlights Session at the CCLG Annual Conference in Manchester**, bringing together researchers, clinical professionals, charities and patient advocates to showcase the wide range of childhood cancer research supported by VIVO, across different cancer types, research questions and approaches.

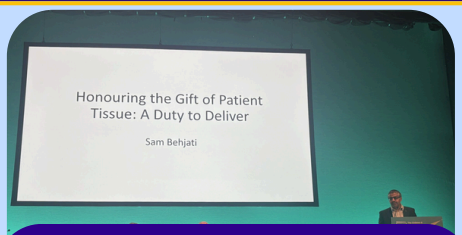
The session highlighted the impact of collaboration across the VIVO network from patient donation to scientific discovery.

Featured Presentations



Sarah Wakeling
CEO, Alice's Arc

Shared a **parent's perspective** on tissue donation, highlighting the generosity of families and the importance of raising awareness on clinical wards so families have the opportunity to consider biobanking and contribute to future research.



Professor Sam Behjati
Wellcome Sanger Institute

Discussed researchers' responsibility to maximise the value of every donated sample, including **post-mortem donations**, highlighting research that showed how these incredibly generous gifts can advance our understanding of childhood cancer and benefit future patients.

Key Takeaways

- Every donated sample has the power to advance childhood cancer research.
- Partnerships between patients, families, healthcare professionals and researchers drive meaningful discoveries.
- Research supported by VIVO Biobank is improving our understanding of childhood cancers and shaping future treatments.
- Biobanked samples are supporting innovative research, from genomic analysis to organoid models, translating patient donations into important scientific discoveries.

RESEARCH IMPACT

A New Immunotherapy Approach for High-Risk Childhood Leukaemia

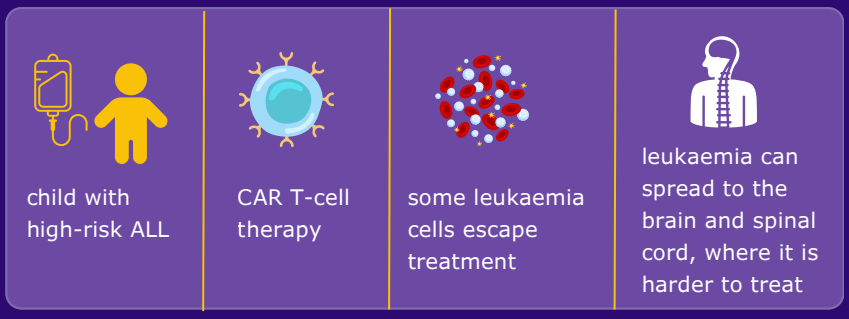
Prof. Anastasios Karadimitris, Prof. Anindita Roy and co-authors

Read the paper
Scan the QR code or click this link to read the full research paper online

VIVO Biobank provided patient samples from children with **acute lymphoblastic leukaemia (ALL)** to support this research into a new dual-target immunotherapy designed to better eliminate aggressive leukaemia and overcome treatment resistance.

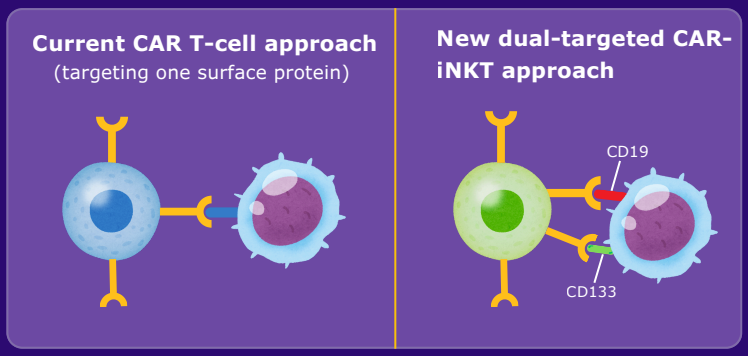
The challenge

Children with a particularly aggressive form of leukaemia (called *KMT2A*-rearranged ALL) are more likely to relapse. In this particular type of ALL, some leukaemia cells can evade current, advanced cell therapies (e.g. CAR T-cell) by changing the proteins on their surface or by spreading to difficult-to-treat areas, such as the brain and spinal cord.



The researchers' approach

Researchers utilised a new CAR-T-based cell therapy approach, called invariant natural killer T (**iNKT**) cells. These cells were engineered to target 2 surface proteins, **CD19** and **CD133**, found on the surface of leukaemia cells, instead of just one. This makes it more difficult for cancer cells to escape detection and improve treatment effectiveness.



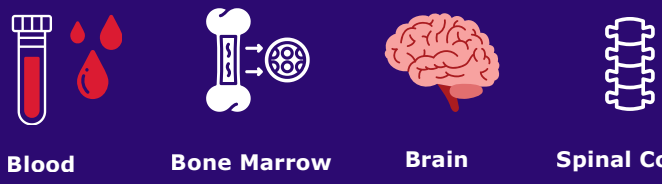
What did the researchers discover?

In laboratory studies and animal models, the dual-target CAR-iNKT cell were more effective than current CAR T-cell approaches at eliminating leukaemia.

Effective in preclinical models

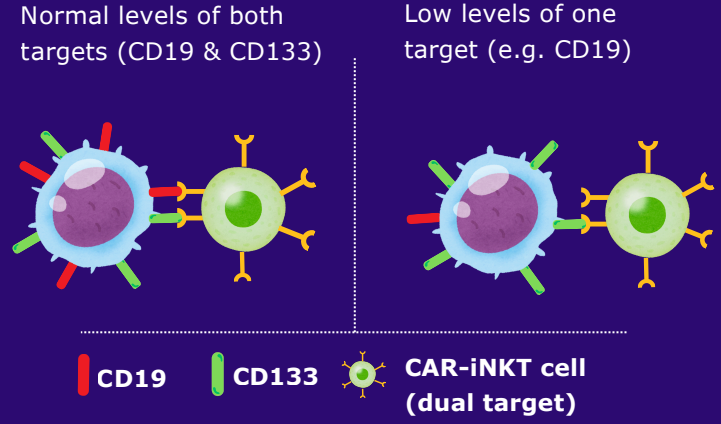
Dual-target CAR-iNKT cells were more effective at eliminating leukaemia cells in both lab models and animal models.

Leukaemia cells eliminated from multiple sites



The treatment successfully eliminated leukaemia from the blood, bone marrow and the tissues surrounding the brain and spinal cord.

Remains effective even when leukaemia cells have lower levels of one target protein



What could this mean for children with cancer?

These findings highlight the potential of dual-target CAR-iNKT therapy as a new treatment strategy for children with high-risk leukaemia. Although the research is still at the preclinical stage and has not yet been tested in patients, it provides strong evidence that targeting cancer in multiple ways could lead to more effective and longer-lasting treatments.

Further research and clinical trials will be needed before this therapy can become part of routine care.

RESEARCH IMPACT

Understanding Which Intermediate-Risk Neuroblastomas May Behave More Aggressively

Prof. Deb Tweddle and co-authors

Read the paper

Scan the QR code or click this link to read the full research paper online

What question were the researchers trying to answer?

Most children with intermediate-risk neuroblastoma have good outcomes with the current treatments. However, a smaller group of these children still experience relapse or their disease progresses. The researchers wanted to know whether specific genetic changes in tumours could identify children in this middle-risk whose disease may be more difficult to treat.

How did they investigate this ?

The researchers studied **98 tumour samples** from children with this rare form of intermediate-risk neuroblastoma from the UK and around Europe. They looked at tumour genetic characteristics, including changes in chromosome structure and specific genes, and compared these findings with how patients had responded over time. They also used more detailed testing in some samples to investigate telomere maintenance and patterns of gene activity.

Tumour Sample → Detect genetic changes → Compare with patients outcomes

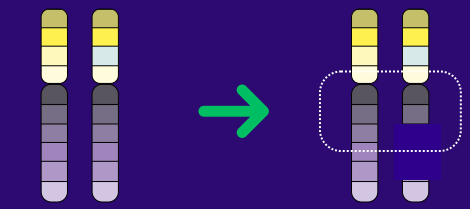
What did the researchers discover?

In this study, researchers found three types of genetic changes in some intermediate-risk neuroblastoma tumours. These changes can make the cancer behave more aggressively and are linked to poorer outcomes.

1) Segmental chromosomal changes

Our cells contain 23 pairs of chromosomes, which carry our genes, the instructions that help control how our cells grow and function.

Segmental chromosomal changes happen when large sections of a chromosome are deleted, doubled and rearranged.

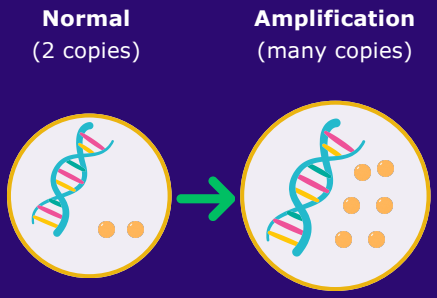


What it means

These large changes can switch important genese on or off, which can make the tumour grow and spread more easily.

2) Oncogene amplification

Oncogenes are genes that drive cell growth. Sometimes cancer cells make too many copies of an oncogene. These leads to the gene being overactive.



What it means

Too many copies act like pressing the accelerator on cell growth, helping the tumour grow faster.

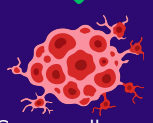
3) p53 pathway alterations

Normal p53 pathway

Protects cells by repairing damage or stopping growth

Altered p53 pathway

Damaged cells continue to grow, increasing the risk of cancer



Cancer cells can grow and survive

The p53 gene is like a "guardian" of the cell. It helps to repair damaged DNA or tells the cell to stop growing if something is wrong.

Alterations in the p53 pathway mean this protection is lost.

What it means

Without this protection, cancer cells can grow and survive when they shouldn't.

What could this mean for children with neuroblastoma?

These findings suggest that looking at specific genetic alterations of a tumour could help better identify children with intermediate-risk neuroblastoma whose tumours may be more likely to behave aggressively. In the future, this information could help doctors and researchers better understand a child's risk categories more precisely and explore alternative treatment options.

Further research and clinical trials are needed before these findings can be used to guide routine treatment.

Why Diversity in PPIE Matters

Cancer research should reflect all the people affected by the disease

Yet some groups, including **teenagers and young adults (TYA)** and people from certain **ethnic and socio-cultural backgrounds**, remain underrepresented in research. Rare childhood cancers can also be less well studied because fewer patients can be recruited in studies.

Research has identified differences in cancer outcomes between ethnic groups, highlighting the importance of **diverse representation in research**. When some groups are underrepresented, research may not fully capture differences in **experience, biology, access to care or outcomes**, which can mean their needs are less reflected in the evidence used to improve cancer care.

Language barriers, complex medical information, cultural differences and limited opportunities to get involved can all make it harder for some people to take part in research or donate samples.

That's why diversity in our PPIE group matters. By bringing together patients and families with different genders, ages, ethnic backgrounds and experiences of childhood cancer, we can understand different perspectives, identify barriers and help ensure our biobank and the research it supports represents everyone.

Want to get involved?

We're looking for more **patients and family members** of those affected by **childhood, teenage and young adult (TYA) cancer** to join our PPIE group. It is important that our group reflects the diversity of the people and families affected by cancer, and we particularly welcome people with different **genders**, **ages**, **backgrounds**, **geographical locations**, as well as those with **lived experience of rare and ultra-rare cancers**.

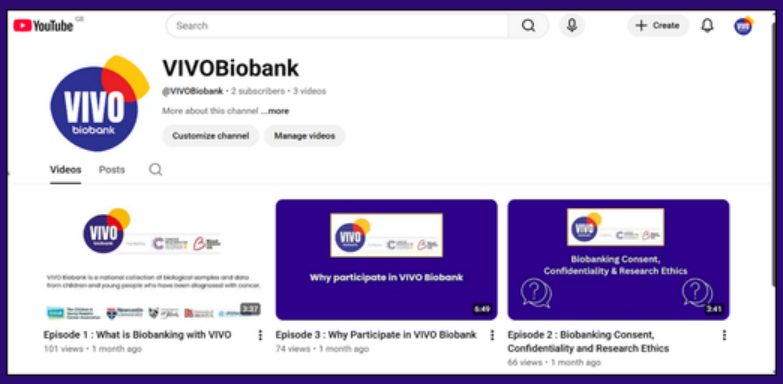
By joining us, you can help ensure that the voices and experiences of all patients and families are heard across VIVO Biobank.

You could help us:

- Review patient-facing information and material
- Shape our website and communications
- Provide a patient perspective on research applications
- Help improve awareness and access to biobanking

PPIE Group in Action

Helping create resources for patients and families



Our PPIE group members recently helped create a **three-part video series** to make information about biobanking with VIVO more accessible and clear for patients and families considering sample donation.

Watch the videos by scanning this QR code →
or on our YouTube channel: @VIVOBiobank

What's involved with the role?

- Around 2 hours per month on average, with most activites taking place online.
- A 3-year role, with the option to continue for 2 addional years.
- No previous PPIE experience or scientific knowledge is needed, just a willingness to share your experiences and being open to different perspectives.
- Optional reimbursement is available for your time, and reasonable expenses such as travel allowance will also be covered.

Interested in joining us?

If you would like to find out more about becoming a VIVO PPIE member, please get in touch with Involvement@vivobiobank.org.