Fighting childhood cancer. Saving young lives.

Annual Review 2013



Foreword by our Chairman



2013 was a vear of achievements both for the charity and, more importantly, for the children and young people we help.

Children like Luke, who achieved his five years in remission in 2013 and whose year you can follow throughout this annual review. I had the pleasure of meeting Luke and his family at our 25th anniversary reception in January 2013. His story reminds us all why we are here.

Thanks to the generous support of friends like you, in 2013 despite the backdrop of financial uncertainty, our income increased to over £12 million.

This enabled us to grant £3.5 million for essential research programmes as part of our continuing focus on helping children and young people with all types of cancer. We will also aim to commit a further £3.5 million specifically for brain tumour research from 2014.

We also invested £2.4 million in welfare grants to provide better care and practical support for young 📞 cancer patients and their families.

I know first-hand how devastating a diagnosis of cancer can be for a family. My own son Paul was diagnosed with the blood cancer leukaemia, when he was 14 years old and died just nine weeks later. Unbelievably, we lost his sister Jean, also to cancer, just nine months after Paul. Our charity was launched in their memory and today, we raise money to help children with all types of cancer.

Whilst we've done much in 2013, we need to do so much more. Brain tumours kill more children than any other form of childhood cancer but that area of research is seriously underfunded. That's why your support is so important to us.

We want to stop childhood cancer. Until we get there, we will continue to fund the best research to improve treatments and keep looking for

ways to prevent children getting this dreadful disease. We are enormously grateful to you and all our dedicated supporters who raise the funds that make this essential work possible.

Together, we can give more children like Luke a brighter future. Thank you.

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Fddie O'Gorman OBE Founder and Chairman of Trustees



Around 2,400 children and teenagers are diagnosed with cancer every year in the UK. That's about six every day.

Thanks to investment in research. more than three quarters of young cancer patients can be successfully treated - there are more than 33.000 survivors of childhood cancer in the UK today.

But we want to give all children a better chance in their fight against cancer.

In the 1960s, only nine per cent of children with leukaemia survived. Thanks to the support of people like you, Children with Cancer UK has funded research to help increase survival to around 90 per cent.



But less progress has been made for children with other cancers. Every year in the UK, around 280 children and around 110 teenagers (aged 15 to 19) lose their lives to cancer.

Tragically, cancer is the most common cause of death in children aged one to 14 years, accounting for around one in five deaths in this age group. Treatment for cancer can involve high doses of toxic chemotherapy drugs and/or radiation. Some children also need extensive surgery to remove their tumours.

"Luke was just six months old when he was diagnosed with a liver cancer. He was such a brave boy and was always so smiley and happy during treatment. He is now a healthy six year old and we are so thankful for everything that Children with Cancer UK does to help children like Luke."

Claire, Luke's mum

The chemotherapy drugs kill the cancerous cells but can also damage normal, healthy cells. Short-term side effects such as hair loss, nausea and anaemia are common but temporary problems.

Some children will experience more serious long-term effects which persist for months or years after treatment, including:

- heart, lung or kidney problems
- impairment of growth
- learning difficulties
- loss of sight and/or hearing
- infertility
- physical disabilities.

That's why our work is important.

We want to make treatments safer and reduce the risk of harmful effects. find new ways to treat children who have a poor prognosis and save more young lives.



This is me!

Luke with special guests at our 25th anniversary event at the House of Lords. (Adults in back row from L-R) John Baron MP, Head of External Affairs Caroline Hampden-White, Trustee Sandra Mileham, our Chairman Eddie O'Gorman and our host Lord Willis

By raising awareness of childhood cancer, we can protect more children and improve the lives of young cancer patients - today and for future generations.

We celebrated our 25th anniversary in 2013. Thanks to you, we've been fighting cancer, giving hope and saving young lives since 1988.

In January, we held our first major parliamentary event as Children with Cancer UK. Hosted by Lord Willis, this was an opportunity for us to celebrate the scientific advances of the past 25 years and raise awareness of childhood cancer.

Celebrating Science

In June, our second parliamentary event was attended by many of the scientists who have made life-saving advances in the prevention and treatment of childhood cancer. thanks to our much-valued supporters. Hosted by Baroness Thornton of Manningham, parliamentarians including John Baron MP, Sharon Hodgson MP. Jim Shannon MP. Mark Tami MP and our famous friend Baroness Floella Beniamin joined us on the day to talk to families affected by childhood cancer.

Both events were essential in raising awareness of our charity among policy makers, enabling us to ensure the best interests of children with. or at risk of developing, cancer are considered in the development of government policies.

This was a wonderful occasion to celebrate our achievements but also to look ahead for improved treatments and a brighter future for all children with cancer.

"Please pass our thanks on to the scientists who work researching and understanding Wilms' tumours. As a rare cancer, it means a lot to know that other children at risk can be screened earlier and treated more effectively.

"Amos, Phoebe's dad, used to be a cancer research scientist and has lots of questions which we hope. over time, can be answered by the research your charity funds.

"All your great work is much appreciated by families like us."

Laura, Phoebe's mum



childhood cancer.

their families.

addressing the public and political concern around

What we're going to do

We will raise awareness of

September is Childhood Cancer Awareness Month. We will join forces with other charities helping children and young people with cancer to raise awareness of the impact of childhood cancer and the need for more support for children, young people and

We will raise awareness of the link between childhood leukaemia and power lines.

In 2014 we'll launch a report childhood leukaemia and the electric and magnetic fields (EMFs) produced by overhead power lines and substations.

It follows up our 2006 report on FMFs and childhood leukaemia and will explore the science behind the concern.

We will understand more about how the public see our charity.

We will measure awareness of our charity and our work by surveying supporters and the general public. By measuring awareness, we can ensure that we understand how to communicate better and fundraise more effectively to achieve our aims.

To find out more about our work to raise awareness. please visit childrenwithcancer.org.uk/ awareness



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Luke with his family at Disney World to celebrate five years in remission

'Thanks to new research into medicines and treatment, Luke achieved five years in remission in 2013. We took him and his brothers on a very special holiday to Disney World, Florida to celebrate. We all had an amazing time!'

Claire, Luke's mum

Look! It's me again with Mickey Mouse!



Through our research programme, we aim to fund projects that help us to understand why children get cancer, improve treatments and save more young lives.

Thanks to your generosity, we awarded £1.38 million to fund nine research projects in March 2013.

These new projects focus on a wide range of childhood cancers including leukaemia, neuroblastoma, brain tumours, bone tumours and soft tissue sarcomas.

Treating children with metastatic Ewing sarcoma

We awarded £243,559 to help Dr Ariadna Mendoza at the UCL Cancer Institute to develop better treatment for children with Ewing sarcoma.

Ewing sarcoma is the second most common bone tumour in children and adolescents. One third of patients with metastatic disease at presentation do not survive five years after diagnosis.

When the cancer spreads to other parts of the body (metastasises), it is difficult to treat and usually fatal.

There is an urgent need to identify the 'drivers' of metastasis and new therapies that will block this process.

"We are building on previous work funded by Children with Cancer UK that has identified a promising new approach to treatment, combining two types of drugs" says Dr Mendoza.

"We have selected drugs that are currently undergoing or have already undergone phase two clinical trial in adult patients with advanced solid tumours. "We will undertake pre-clinical experiments to build the evidence necessary to test this drug combination in a clinical trial for young patients with Ewing sarcoma.

"This method may be less toxic than chemotherapy and could reduce side effects. It may also reduce tumour resistance to treatments and allow for lower doses of drugs, further reducing risk of toxicity."

This research could improve the quality of life - and the life expectancy - of children with metastatic Ewing sarcoma who have a very poor outlook.



Understanding leukaemia in children with Down syndrome

We awarded £693,257 to Professor Paresh Vyas and Professor Irene Roberts at the University of Oxford to support their research into the development of leukaemia in children with Down syndrome.

Children with Down syndrome have an increased risk of developing acute myeloid leukaemia (AML) - a cancer of the myeloid blood cells.

Down syndrome is caused by the presence of an extra copy of

chromosome 21 in a baby's cells. As well as causing Down syndrome, this extra chromosome affects blood cell production in the developing foetus. This is linked to the development of a pre-leukaemic condition called transient abnormal myelopoiesis (TAM), which is present at birth in at least 10 per cent of children with Down syndrome.

In as many as one third of the children born with TAM, additional genetic changes convert the pre-leukaemic stem cells into full blown leukaemic stem cells, leading to the development of leukaemia. In the remaining children, the TAM simply disappears.

The Oxford team is trying to understand how the extra chromosome 21 disturbs foetal blood cell production and precisely what

"Hollie was given the all clear in December 2012 so we had a huge celebration. She's been so strong and brave and makes me so proud."

Hollie's mum, Hayley

additional genetic changes cause the transition from TAM to full-blown leukaemia. They are studying a gene called GATA1 which is known to play a role in this process.

Through this work the team hopes to improve the diagnosis and management of blood problems in babies with Down syndrome and even to prevent the later development of leukaemia.

This work will also inform our understanding of leukaemia development in children who don't have Down syndrome.

To find out more about these and other projects that you have helped to fund, please visit childrenwithcancer.org.uk/ research



Luke with his mum Claire and our host Baroness Thornton at our House of Lords event in June to Celebrate Science

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Call and the second

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MART CARLESSING

June 2013

We met lots of

clever scientists and

heard all about what

they're doing to help children like me.



We are partnering with The Brain Tumour Charity and Great Ormond Street Hospital Children's Charity to fund a £4 million research programme into childhood brain tumours over five years.

Brain tumours are the second most common childhood cancer, with around 400 children diagnosed every year in the UK. More children die from brain tumours than any other cancer and for those who survive, aggressive treatments can cause serious long-term disabilities.

We desperately need to fund more research to improve our understanding of childhood brain tumours and improve the outlook for young patients. Improving treatments for children with brain tumours

In December 2013, we awarded £980,946 to Professor Steven Clifford at the Northern Institute for Cancer Research (NICR) at Newcastle University and the overall lead for the INSTINCT programme.

The five year programme brings together three of the UK's leading paediatric neuro-oncology centres - the NICR, the UCL Institute of Child Health and the Institute of Cancer Research - to develop new therapies.

Professor Clifford explains: "The benefits that we're trying to bring to children with brain tumours are two-fold. Through understanding the biology of brain tumours in much more detail, we hope to be able to increase the cure rate for children with brain tumours.

"And for those children that survive their brain tumours, we also want to make sure that their quality of life is as good as it can be following their treatment.

"Funding for INSTINCT's work is critical. The money for this new programme will underpin our efforts for the next five years to allow us to make new biological discoveries and move those forward into the clinic."

"We hope to increase the cure rate for children with brain tumours and make sure that their quality of life is as good as it can be following treatment."

What we're going to do

We want to drive forward research into childhood brain tumours, reduce side effects and save more young lives.

In 2014, we are launching our Brain Tumour Initiative, a three year programme to increase momentum in childhood brain tumour research and encourage collaboration between those working in the field. We will launch the first call for applications in February 2014 and expect to award the first grants before the end of the year.

As well as this dedicated investment, we are also funding important brain tumour work through our existing channels.

"Lucy has a brain tumour and fights her little heart out every day, nearly always with a smile and a wave. Her resilience and spirit are inspirational. Lucy is still under close observation but thanks to research and treatment, we feel really positive about her future." Sarah, Lucy's mum

In 2014 we will fund our first ever research fellowships, at least one of which will focus on brain tumours. We will also announce a new round of project grants in May and several of these will also focus on brain tumours (see page 19 for further information).

To find out more about these and other projects that you have helped to fund, please visit childrenwithcancer.org.uk/ research



(From L-R) Luke with Professor Tariq Enver, Acting Director of the UCL Cancer Institute at the Paul O'Gorman Building, University College London, Pippa Gough f our charity, Luke's mum Claire an grandparents Sally and Jim

cancerUK

This is me with one of the scientists showing me some of their work

Summer 2013

went with mummy

and my grandparents to learn stuff about

cancer - Children

scientists lots of

money every year to help more children

like me.

with Cancer UK give



In December 2013, we awarded a total of £390,000 for nine innovative start-up projects in different areas of childhood cancer research.

The grants are capped at £50,000 for projects lasting up to 12 months and are targeted at early career researchers to help get important new work off the ground.

The nine projects are concerned with a broad range of childhood cancers including leukaemia, lymphoma, osteosarcoma and neuroblastoma.

Tailoring treatments to reduce the risk of heart damage

We awarded £49,982 to Dr James Allan and Dr Sujith Samarasinghe at Newcastle University to identify genes which may contribute to the risk of heart damage in children having chemotherapy. Drugs known as anthracyclines are one of the most effective chemotherapy medicines and are used in the treatment of many childhood cancers. Unfortunately, one of the side effects is a form of severe heart damage called cardiomyopathy.

Because of this risk, the doses of anthracyclines are often reduced, potentially compromising the child's chance of cure.

The research team will screen the genes of children who have developed severe cardiomyopathy to look for common genes that may determine the risk of heart damage.

This would ultimately enable doctors to screen children before treatment and tailor treatment accordingly.



"I was two years old when I was diagnosed with leukaemia. I'm absolutely fine now but need to get my heart checked every 18 months as I've got an enlarged ventricle they are keeping an eye on." Sam, aged 16

What we're going to do

We will fund research to improve our understanding of childhood cancers and take forward the development of new treatments to improve both the rate and quality of survival.

Our 2013 project grant round will conclude in spring 2014. Our Scientific Advisory Panel must now make difficult decisions about which of the 20 projects under consideration offer the very best opportunity for progress. We hope to fund eight or nine of these projects, at a cost of around £2 million.

We will award our first Postdoctoral Research Fellowships in the summer of 2014. These Fellowships aim to support outstanding scientists seeking to develop a career in childhood cancer research. At a cost of £400,000 each, the Fellowships will include funding for a defined five year programme of work. We hope to make three awards. We launched our Brain Tumour Initiative in February 2014, as set out on page 15, and will make the first major project grants out of this scheme at the end of the year.

We will launch a further call for project grant applications (all childhood cancers) in the summer of 2014. We hope to allocate around £2 million to research projects that promise important new insights into the development and treatment of childhood cancers. This grant round will conclude in spring 2015.

We will encourage the sharing and dissemination of information about research relevant to childhood cancer to promote best practice.

In June 2014, we will host a two day international workshop focusing on the mechanisms by which environmental agents may act on an unborn child to increase their risk of developing cancer. World-leading experts will gather to consider and discuss the latest evidence and aim to identify gaps in knowledge.

In late 2014, we will host a workshop focusing on the biology underlying the association between childhood leukaemia risk and exposure to electric and magnetic fields. This focused event will bring together a small number of leading experts to consider the current state of knowledge and map out a path for ongoing research.



Luke with our VIP guests at Zippos Circus, performers and CBeebies presenter Pui Fan Lee (centre)

Can you see me? September 2013 Children with Cancer UK invited us all to the circus with lots of other children. Some were still Poorly but we all had loads of fun! 21

When a child is diagnosed with cancer. their treatment normally starts immediately, is often given far from home and can last for years. Your generosity has helped to fund welfare projects across the UK to provide better care and practical support for young cancer patients and their families.

Birmingham Children's Hospital

£1 million to help build a new children's cancer unit and upgrade existing facilities.

The new building and accommodation will include more comfortable treatment areas and consulting rooms, age-appropriate play zones, better communal areas for families and an improved outpatients area.

2 Bristol Children's Hospital

£500,000 to help transform facilities on the new Integrated Cancer Unit.

Your donations will also enable the hospital to invest in a ground-breaking Paediatric Intraoperative MRI Scanner. The scanner - the first of its kind in the south of England and only the third in Europe - will revolutionise treatment and boost survival rates for children with brain tumours.

3 CLIC Sargent, Belfast

£375,000 to help launch Paul's House, a new 'Home from Home' in Belfast.

The first of its kind in Northern Ireland, Paul's House provides free accommodation for families whose children are having cancer treatment at the Royal Belfast Hospital for Sick Children.

Each week two children and young people in Northern Ireland are told they have cancer. On average, a family will make a round-trip of 95 miles, up to five times a week to access the cancer treatment their child needs in Northern Ireland.

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"Thank you once again for another great day out. The girls really enjoyed themselves. Nothing you do goes unnoticed and is always very appreciated. We loved the cards on the tables, such heartfelt wishes," Kathi. Vega's mum

Here's Vega

4 Zippos Circus, London

Thanks to your kind donations, 44 children with cancer and their families enjoyed a unique day out at the circus.

Our VIP quests were treated to a sensational circus extravaganza featuring over 20 performers and a special lunch in their own Mini Big Top!

Watch our video of the day and some special thank you messages at childrenwithcancer.org.uk /zippos

What we're going to do

We will support more young cancer patients and their families.

We will continue to work with our charitable partners and hospices to help provide better care for children with cancer and their families.

Our special day out at Zippos Circus is extremely popular with families and we hope to organise another event in September 2014.

We will provide more information about childhood cancer.

We will develop our website to provide more information about the different childhood cancer types for parents and families. We will work with more families to share their stories and help others who have been affected by childhood cancer.



Fundraising highlights







Luke and his family with Chef Dominic at One Aldwych hotel (centre), Charlotte and Phoebe (cancer survivors), Phoebe's mum and baby sister



Fundraising highlights

We can only continue our fight against childhood cancer with support from people like you. In 2013, you helped to raise over £12 million. We don't receive any funding from the government so every penny you donate makes a huge difference. Thank you.



To mark our 25th anniversary, over 1,300 Children with Cancer UK runners jointly ran more than 25,000 miles (the world's circumference) in the Virgin London Marathon, raising over £2.5 million.

Generous guests were treated to a fantastic performance from Madness at our annual fundraising ball, raising over £460,000. Our celebrity guests including Stephanie Beecham, Charlie Brooks, Helen Flanagan and Lesley Joseph made the evening extra special.

> £10,000 was donated by our Ball guests for 20 Disney on Ice tickets for children with cancer and their families. "It was a brilliant evening and I have never known my three daughters to sit so still and transfixed. Thank you so much to your supporters who put a smile and magic into my daughters' lives." Sarah, mum to Esme. Esme was diagnosed with leukaemia when she was three years old.

220 cyclists raised over £200,000 in the first Prudential RideLondon – Surrey 100, the biggest cycling sportive ever held in the UK. 2012, Toys "R" Us raised almost £77,000 from the sale of their specially designed carrier bags

From the start of our partnership in August



Majestic Wine Warehouse raised £54,646 from store collections, product promotions and staff fundraising.

a fourth year!

St. Baldrick's fundraisers raised £41,000 through a series of head-shave events in the UK. St Baldrick's is a worldwide organisation. Through this partnership, proceeds from their head-shaving events were donated to Children with Cancer UK to support our research work in the UK.

Barker Ross raised £25,000 to celebrate their and our

25th anniversaries.

They organised a family fun day, a charity dinner and took part in an abseil, skydive and

trekked Snowdonia to raise funds.

Nearly 60,000 people supported our Summer Grand Draw, raising over $\pounds 1$ million for the first time! Our Christmas Grand Draw raised a further $\pounds 1.4$ million. Our sincere thanks to Sir David Jason and our trustee Linda Robson for launching our appeals.

and IT upgrade.

Chris Tarrant once more hosted our Quiz Party, helping to raise over £108,000 for Children with Cancer UK.
The KPMG team were the winners for



We were delighted that Lombard extended their partnership with us for a third year. In addition to having raised over £275,000 for the duration of the partnership, they have provided invaluable help and support in improving our operations, facilities Elizabeth, leukaemia survivor aged eight, designed a postcard for our supporters to share a special message with our guests at Zippos Circus. Supported by children's presenters Chris Jarvis and Pui Fan Lee from CBeebies, this appeal raised nearly £275,000.



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Deloitte.

A special thank you to Deloitte

We had the greatest pleasure in working in partnership with Deloitte from January 2010 to May 2013.

Over £2 million was raised by staff and split between us, Cancer Research UK and Help for Heroes. We received £700,000 and over £80,000 of pro bono support.

Deloitte's generous donation is helping to support the current national clinical trial for children with acute lymphoblastic leukaemia (UK ALL 2011) and the establishment of a national childhood leukaemia cell bank.

We were thrilled by the time, energy and commitment everyone in the firm has put in to supporting all three charities for three and a half years. A huge thank you to everyone involved.

What we're going to do

We will develop our fundraising appeals to raise more money and help more children with cancer.

We will launch a new spring raffle and an online raffle to complement our successful summer and Christmas activities.

We will launch a national fundraising campaign in 2014 to encourage a further 10,000 people to support our work with a regular donation by the end of 2015. This essential income will help us plan our future research and welfare projects.

We will welcome more people onto our running, cycling and trekking teams.

We have over 300 places for Prudential RideLondon – Surrey 100 event in 2014, making this our key cycling event for 2014. We will host our first bespoke trekking challenge in September. Join us for a challenging 24 hour hike over Ben Nevis, Scafell Pike and Snowdon and help save young lives!

We will continue to be honest and open about our fundraising

We will improve our service and continue to give a high standard of care to all of our supporters.

Our Supporter Care Charter

- We recognise the true value of each and every supporter
- We respect our supporters
- We value supporter relationships
- We know who our supporters are
- We listen to your feedback
- We go "The Extra Mile".

To find out more about how you can get involved, please visit childrenwithcancer.org.uk/ fundraising-and-events

How your donations help children with cancer

We are pleased to report an increase in our incoming resources to over £12 million in 2013.

This has allowed us to fund almost $\pounds 6$ million in essential research and welfare programmes to help more children with cancer – the highest we have ever funded in one year.



For every £1 we spend on fundraising, we raise over £5 more.

To view our full financial statements for 2013, please visit childrenwithcancer.org.uk/review2013

more money

childhood cancer

For every £1 you donate, we spend 84p on fighting

43p on research projects 28p on welfare projects 13p on raising awareness 1p on governance and support We invest 15p in £1 to raise

Our total fundraising income

- Appeals: 33%
- Running: 27%
- Corporate, trusts: 7%
- Committed giving, legacies: 18%
- Special events, trading: 6%
- Other: 9%





Thank you

- A warm thank you to all of the families featured in this Annual Review and to all those who have kindly shared their experiences. Your involvement is essential in raising awareness of childhood cancer and raising money to fund our work.
- Runners and challenge participants especially Gillian Clason, Kieran McCarthy and Mike Levitz.
- All those who have organised their own fundraising events, including the MAD Ball Committee who raised over £33,000 in February 2013, St Baldrick's and Mark Newton-Jones.
- Our dedicated Ball and Quiz chairs and committees especially Rob Templeman, Mick Keating, Margrete Hargreaves-Allen and Lady Julia Craig Harvey.
- Zippos Circus and Martin Burton.
- Cos Onisforou at Fare for providing free food and drink at Zippos Circus.

- Our Scientific Advisory Panel, our Scientific Advisors and specialist peer reviewers.
- And finally, a special thank you to our dedicated and passionate team of staff at Children with Cancer UK.

Celebrity Fundraising Friends:

Ant & Dec • Cilla Black Brenda Blethyn • Sir Michael Caine Jasper Carrott • George Cole Joan Collins • Phil Collins Ronnie Corbett • Dame Judi Dench Sir Bruce Forsyth

Sir Chris Hoy Chris Jarvis • Sir David Jason Pui Fan Lee • Lennox Lewis Gary Lineker

Joanna Lumley Sandy Lyle • Des O'Connor Sir Paul McCartney • Sir Trevor McDonald Robert Powell • Pauline Quirke Sir Steve Redgrave

Linda Robson Jonathan Ross • Phillip Schofield Stacey Solomon • Chris Tarrant David Tennant • Dennis Waterman Kevin Whately • Paul Young



Whether your company is big or small, you can help us give children a better chance in their fight against cancer.

We have some exciting Charity of the Year partnerships for 2014 including Coral, the sports betting shops, which we are delighted to have won through a staff vote. If your company has a charity of the year scheme you may be able to nominate us!

To find out more about corporate opportunities, please visit childrenwithcancer.org.uk/corporatefundraising or contact us at corporate@childrenwithcancer.org.uk



Children with Cancer UK is the leading national children's charity dedicated to the fight against childhood cancer.

Read our Annual Review online, watch videos, download our complete Annual Report and Accounts 2013 and full list of our Grant Awards at **childrenwithcancer.org.uk/review2013**

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