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Find out more about our  
existing funds and how  
to set one up yourself!  
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Patient Info Day  
6th March 2012  
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# brain tumour

across  
yorkshire

research and support



We are Yorkshire's leading brain tumour  
charity, providing funds for brain tumour  
research and patient support.

incorporating  
andrea's gift



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31  
**£2 Million**  
target date



Charity Newsletter | 2012

# Can you help us in our biggest challenge so far?

Raising £2 Million by the end of 2013. Page 3 for more!



Ellie's Fund  
Brain Tumour Trust

Working together. Find out how we come together to fund joint projects. See Page 6





## *Why we changed our name from Andrea's Gift to Brain Tumour Research and Support across Yorkshire (BTRS)*

Andrea's Gift, Yorkshire's leading brain tumour charity was founded in 2003 in memory of Andrea Key who was 42 when she died from an aggressive brain tumour, seven months after diagnosis.

Andrea's Gift registered as a charity with the sole aim of funding research and providing improved patient support for anyone affected by a brain tumour in Yorkshire. The charity changed its name from Andrea's Gift to BTRS in 2011 as the charity trustees believed this change would help us to connect more easily with patients and their families, medics and nurses in Yorkshire, however, Andrea remains core to our values and everything we do and is a huge part of the charity.

## **Editorial**

*Hi there... my name is Greig Robertson, Editor of the Brain Tumour Research and Support across Yorkshire (BTRS) Newsletter.*



I aim to make this newsletter as informative and supportive as possible and welcome any contributions you would like to make. Please send any information you would like to see in the next issue to me at [contact@btrs.org.uk](mailto:contact@btrs.org.uk). Also if you have any suggestions for new articles, just let me know.

Keep up to date with charity news by visiting our web site at [www.btrs.org.uk](http://www.btrs.org.uk) and help us to continue to build on our solid foundation.

Please join in some of our events such as Wear a Hat, Target £2m, or if you are a patient come along to our Support Group or Support Suppers we would love to meet you! For the more energetic, why not sign up for one of our bike rides, the Lyke Wake Walk or Yorkshire Peaks trek or perhaps you can take part in one of the many organised events there are over the summer months, let us know and we will help you get organised by giving you a sponsor form, tee shirt or running vest to take part in.

Looking forward to hearing from you soon!

Greig

# Target £2 Million

*Target £2 Million is a campaign which we hope will result in Brain Tumour Research and Support across Yorkshire (BTRS) hitting its target of £2 Million raised before the end of 2013 as part of their 10th Anniversary celebrations.*



BTRS want to engage with corporate organisations across Yorkshire and Humber and encourage them to raise funds as part of their Corporate Social Responsibility policy; those organisations that may in some way have been affected by a brain tumour story or who may wish to support work in the region that they are based.

We also want to connect with more patients across the region, there is an effective support network in place, we simply need to connect with the people we can help.

Through the appointment of voluntary Charity Ambassadors, those with a high regional profile as well as patients and carers with

a story to tell, BTRS will be able to spread the word about their work at events, conferences, within the community and across the regional media; could you be an Ambassador and can you help us on the next stage of the journey?

For more information, contact Carol at [contact@btrs.org.uk](mailto:contact@btrs.org.uk)

## Support Group

*The BTRS support group meets from 6.30 to 8.30 on the first Tuesday of each month.*

The group meets at the Crowne Plaza Hotel, Wellington Street, Leeds LS1 4DL, but please ring Carol on 01943 870770 to confirm the meeting place as we sometimes change and will have supper in a local restaurant.

This group welcomes brain tumour patients, families and carers into an informal environment where we chat, have a frothy coffee, cup of tea (or something stronger!) We are joined in some meetings by health professionals, Dr Sean Lawler, neuro-oncology scientist, George Madine, our counsellor and other guests. Some meetings we just chat together.

2012 will see the launch our Support Suppers. The first Supper will be in York and the purpose is to bring patients and their families together just to chat and share common experiences. Other planned Suppers include a Supper in Skipton for parents in North Yorkshire who are caring for a child with a brain tumour and a Leeds based Supper for those who have lost a loved one to a brain tumour. Please contact Carol on [contact@btrs.org.uk](mailto:contact@btrs.org.uk) or call 01943 8700770 for more details.

Support Suppers are free of charge for all patients, carers and family members.



# Our Charity Funds

We currently have seven Funds under the BTRS banner. These Funds help the charity to develop and give families affected by brain tumours something positive to focus upon.

Working with BTRS in this way is the most practical and effective way to develop

an identity and a project that will benefit others. Administration costs are kept to a minimum, Funds can use the charity registration number, benefit from BTRS' public liability insurance and advice is on hand from a charity fundraiser who has 10 years experience in this field, and has access to doctors,

nurses and scientists who work daily with brain tumour patients and science who will guide and advise on specific projects.

We can help you with graphic design and a logo, produce leaflets, posters etc and create a web page to build your Fund identity.

BTRS is very much open to suggestions on how any money raised in a Fund is invested. It maybe you have identified a niche in the area of patient care and support or perhaps you would like to fund a piece of research that is personal to you. Whatever your thoughts, the BTRS trustees are open to your ideas for development. If you want to know more about the Funds, contact Carol or see [www.btrs.org.uk/funds](http://www.btrs.org.uk/funds)



## Louby's Lifeline

Louby's Lifeline began in 2011 when Louby (Laura Robertson-Tierney) was recovering in hospital after collapsing and being diagnosed with two brain tumours. Louby left hospital after seven months and is continuing her recovery at home in Malton. £6,551 has been raised for Louby's Lifeline by friends and family.



## Karl's Fund

Karl Martin, a 32-year-old father of two was diagnosed with a Grade 2 Glioma in 2006. Karl and his supporters have raised a total of £6,609.80, well over half way of their target of £10,000 through sponsored walks, charity music nights, tombola's, jumble stalls, raffles and the selling of bead bracelets.



## Daniel's Gift

2011 saw the Wilkinson family fundraising effort break through the £20,000 barrier! The Wilkinson family have been involved with the charity since 2004 when Dan was diagnosed and whilst recovering from surgery on Ward 48, and mum Tracey started to collect donations from visitors in Dans (empty!) sick bucket!



## Isobel's Gift

Isobel's Gift was established in 2010 to fund support for patients and research across Yorkshire and has raised a spectacular £15,005 since it was launched in memory of Isobel May Crawford who lost her battle with a brain tumour aged 4.



## Harry's Star

Harry's Star has already targeted a particular area to focus their energy, which aims to raise £50,000 to support children and families affected by brain tumours in North Yorkshire. £28,127 has already been raised towards the target.



## Caitlin's Fund

Caitlin's Fund has raised £15,000 with Caitlin getting stronger all the time and continuing to fundraise for BTRS through our annual bike ride, a two hour aerobathon, a fishing match and a sponsored haircut, proving that every Fund can be adapted in order to be as personal as possible.



## Kiah's Dream

Kiah's Dream is the latest BTRS Fund! Kiah's family want to support the TTAP campaign and help other parents when they discover their child has a brain tumour.

# Update on Research Activities

## Dr Sean Lawler

It has been an exciting first year in the Brain Tumour Research lab at Leeds Institute of Molecular Medicine. I have been busy establishing collaborations, starting new projects, and writing grant applications. It is critical to obtain additional funds to build up the research team – I am happy to report that we were recently awarded a Yorkshire Cancer Research Project Grant which will support a researcher in the lab for three years.

The research team currently consists of myself, Dr Lynette Steele (Senior Technician), Priyank Sinha (Neurosurgery fellow), and our most recent recruit Dr Jane Levesley (Post-doctoral Research Assistant). For the summer we were joined by Andy Ditchfield, a Leeds lad, who is studying Medicine at the University of Edinburgh. The new grant will



Right to left: Lynette Steele, Priyank Sinha, Sean Lawler, Marjorie Boissinot, Jane Levesley.

allow us to employ another researcher starting in spring 2012. The lab is focussed on identifying new approaches that will improve the outcome of patients suffering from brain tumours. We have just started a brain tumour tissue bank, which will play a central role in this effort. We have ongoing studies to bring forward a novel treatment strategy which I discovered in my previous lab in the US, as well as new studies investigating ways to kill brain tumour cells by interfering with their metabolism. I have also been out and about telling the UK and European research communities we are here, and what we are doing.

Collaborative studies with local doctors and scientists are being

established with the intention of bringing new clinical trials forward in the coming years. The defining feature of the first twelve months here has been meeting patients and families affected by brain tumours, and the fundraisers whose magnificent efforts have allowed us to get this initiative started. There is a real buzz now about brain tumour research here – Leeds is now part of the international brain tumour research community and I am sure we will grow rapidly over the coming years, which will ultimately lead to improved care for local patients.

*Sean*

# Working together to cure brain tumours

## e-Petition Raising Awareness and Funding for those affected by brain tumours



Proud member of  
**Brain Tumour Research**  
Funding the fight

*By working corroboratively with other brain tumour charities and organisations, we stand the greatest chance of being heard by those in office which really can effect change for brain tumour patients and research.*

BTRS is a member charity of Brain Tumour Research, a national umbrella charity that pulls together 18 other charities. We all work together with the wider group of charities that make up the Brain Tumour Consortium and are all supporting the e-petition below. Please log on and sign up - it is one way to make a BIG difference.

BTRS and Brain Tumour Research through the Brain Tumour

Consortium are calling our supporters to sign a Government e-Petition designed to trigger a parliamentary debate on how best to raise awareness and funding for those affected by brain

tumours <http://epetitions.direct.gov.uk/petitions/17419>

The petition was launched by Rachel Clark and has already attracted thousands of signatures but the Brain Tumour Consortium is backing Rachel's petition in order to draw attention to the 'three asks' we have set out in our manifesto.

These are to:

- Ensure early diagnosis and treatment by ensuring that clear guidelines on identifying the signs and symptoms of brain tumours, and on referring patients for rapid and appropriate assessment, are integrated into General Practice and Emergency Medicine Practice.
- Implement NICE's best practice guidance by

setting a clear timetable to fully implement and audit the Improving Outcomes Guidance, or its country equivalent, in particular by ensuring that the Health and Social Care Bill maintains the progress made to date.

- Increase Government investment in brain tumour research and more accurately measure numbers of both primary and secondary brain tumours by publishing a detailed breakdown of site-specific brain tumour research funding from the
- Government and ensure that by 2014 at least 7.5% of adults with primary brain tumours are enrolled in randomised, controlled clinical trials as part of their therapy.

More details about our three asks can be found in the Brain Tumour Consortium Manifesto on the following link:

[www.braintumourconsortium.org.uk/pdf/Brain%20Tumour%20Manifesto%202011.pdf](http://www.braintumourconsortium.org.uk/pdf/Brain%20Tumour%20Manifesto%202011.pdf)



## Yorkshire 3 Peaks

**Saturday 21st April 2012**

The first 26 mile trek up and over the three Yorkshire Peaks will take place on Saturday 21st April 2012.

Register your interest at [contact@btrs.org.uk](mailto:contact@btrs.org.uk).

## Ambassadors!

We are delighted to announce the development of community and celebrity ambassadors. As the charity expands we need to connect with more people to promote BTRS, particularly with the business community. Recent celebrity ambassadors include Hollyoaks actor Rob Norbury and Radio Leeds Presenter Liz Green.

## March is Brain Tumour Awareness Month

We are going to "Shout it from the Rooftops" ...can you do the same?

March 1st we are going to flood social networking pages with messages to raise awareness about brain tumours. We hope that every patient and supporter who has a Twitter, Facebook, LinkedIn account will join in by posting a series of pre written messages about brain tumours. Email [contact@btrs.org.uk](mailto:contact@btrs.org.uk) and we will keep you updated, or follow us on Twitter @TilesforTumours.



## Meek's Feats Update



In 2009 brain tumour patient and local superstar Ian Meek decided to set himself a massive challenge and raise £100k to fund brain tumour research in Leeds.

He started his campaign in 2010 when he led 60 people over the national three peaks raising £55k. In 2011 he and 20 family and friends cycled 200 miles in 24 hours from Bristol to Bradford raising a further £30k. For 2012 the challenge is even greater as Ian and 120 friends plan to cycle almost 1000 miles from Lands End to John o'Groats.

At the end of 2011 Ian was admitted to the Leeds General Infirmary for his 5th craniotomy and a procedure to de-bulk a part of his changing tumour. The latest surgery left Ian with peripheral vision issues and some hearing problems, but he remains positive and determined to crack both LE2JOG and this disease!

To sponsor Ian and the team, visit [www.justgiving.com/meeksfeats](http://www.justgiving.com/meeksfeats)

## Meeks Feats 130 mile Cycle

For those who fancy a serious cycle challenge, we will be riding 130 miles Wetherby – Scarborough – Wetherby on Sunday 3rd June 2012, taking the same route as the Big Bike Ride and returning the same way. The event will start and finish at the Riverside Car Park in Wetherby.

When completed, a number of riders and their families will head to the Days Inn hotel Wetherby, where we will stay overnight and recover in the bar!

Both events are open to anyone, but we do advise that you do sufficient training in order to avoid injury. We ask all participants get as much sponsorship as possible. Every contribution helps! Hope to see you soon.

## Patient & Carer Information Day, The Thackray Museum, Leeds

*Tuesday 6th March*  
1100 - 1500

Working together with Leeds neuro health professionals, a Patient Information Day has been organised in March. It is an opportunity for patients and carers to meet with health professionals involved in your care, chat to charities and services

who may be able to help you plus a chance to listen to our lunchtime speakers from the fields of brain tumour research, neuro pathology, surgery and oncology. A light lunch is provided and cakes, coffee and tea are available all day.



## Lyke Wake Walk

*Saturday 7th July 2012*

The Lyke Wake Walk is a 42 mile trek across the North York Moors which has to be completed under 24 hours with an average time of 16 hours. If you fancy a physically gruelling midyear challenge,

please register at [contact@btrs.org.uk](mailto:contact@btrs.org.uk) leaving the names of the people who wish to take part. If you are not up to the walk, but can support us in other ways such as marshalling along the route, be at designated stop points to give the walkers water, food, dry clothing etc. please get in touch!

# Celebrating Andrea Key

Thursday 24th May 2012 at The Alhambra Studio, Morley Street, Bradford

On 16th May 2002 age 42 years, Andrea Key died in the Bradford Marie Curie Cancer Care hospice. We thought that it would be fitting to celebrate both Andrea's life and the legacy she left behind in Andrea's Gift and Brain Tumour Research and Support across Yorkshire (BTRS). So, we decided to hold an event in Bradford that will mirror many of the things that Andrea enjoyed. Hayley Walsh

was one of Andrea's friends and is now a professional singer known as Hayley J. Hayley J has agreed to comper and perform during the evening which will be filled with music, comedy and rock n roll jive dancing. Tickets are £8 each and there will be a raffle and auction. We expect the event to be a massive sell out, so please book early!



## Wear a Hat Day

Friday 30th March 2012



Proud member of  
**Brain Tumour  
Research**  
Funding the fight

National charity, Brain Tumour Research organise the annual Wear a Hat campaign and as BTRS are a member charity of the group, we want to support! It is a simple concept - get as many people as you can to organise a

Wear a Hat day at work, school, the gym or anywhere you can find a group of people and donate £1 to BTRS, helping us to raise desperately needed funds for brain tumour research.

We also have some fab little hat pin badges for sale too. If you want to join in and need posters, leaflets and pins, please contact Carol on 01943 870770 or [contact@btrs.org.uk](mailto:contact@btrs.org.uk)

Funding the Fight with Brain Tumour Research  
[www.braintumourresearch.org](http://www.braintumourresearch.org)

## Big Bike Ride 63 Miles

Saturday 12th May 2012

The BTRS Big Bike Ride takes place on Saturday 12th May 2012 and takes a route from Wetherby to Scarborough in what totals a gargantuan 63 miles!

We need riders, so if you fancy the challenge, register at [contact@btrs.org.uk](mailto:contact@btrs.org.uk)



BTRS Cycle Jerseys are available from our website for only £35 so show your support whilst struggling towards the fabled seaside fish and chips!

There is transport home for riders and their bikes for £10 pp - you can pay online at [www.justgiving.com/wetherby-scarborough2012](http://www.justgiving.com/wetherby-scarborough2012)

## Counselling Services

Staff at South Elmsall branch of the Yorkshire Building Society wanted to get involved with BTRS when their friend and colleague, Janet Cox was diagnosed with a brain tumour. Kind staff members applied to the YBS Foundation and secured a donation of £2,000 to keep the service running!



Access to counselling services can be a lifeline for many families and whilst many people recognise the signs that they are under immense pressure and stress,

access to counselling services is often difficult and expensive with many GP's budgets simply unable to stretch to paying for the service.

BTRS provide carers and family members with immediate access to a counsellor, it can take a little longer for patients as we need to work with

the patient's consultant to ensure the right counsellor is provided.

Counselling can provide you with coping strategies to help the

family through some traumatic times and also someone to listen who will be supportive, practical and not judgemental.

All sessions are completely confidential and are arranged at a time you choose and take place in your own home or somewhere convenient to you.

If you feel that you or a family member would benefit from counselling, please contact Carol who will arrange the type of service that will benefit you the most.

# How funds are spent

*Over the past 18 months BTRS has invested money in the following projects:*

### Christmas Party, Summer BBQ, Support Dinners



Bringing patients and supporters together is something that is often hugely beneficial for everyone concerned. Children who are patients feel safe in an environment where they are surrounded with people who understand everyone's needs.

Each party costs around £2,000 with gifts for every child an absolute must!

### Ward 75

Ward 75 (formerly ward 48) is the new paediatric neurosurgical ward. When the team moved into the ward they found that they had more space but no TVs.

BTRS joined together with Ellie's Fund and Levi's Star (two Yorkshire children's brain tumour charities) and organised the purchase of 8 TV and DVD players for the beds. Each charity has agreed to also fund the redecoration of the ward and to provide some child friendly wall art to make the ward look a little more welcoming. Current spend is £1,800 with more to follow!

### Patient Grants

Around £2000 is awarded in patient grants each year. Grants can be for practical items, equipment to make life easier or used towards a holiday or day/evening out.

### Research

At last the research centre is up and running! It costs BTRS £75,000 each year to pay our share of £150,000 annual costs to run the lab. BTRS and Yorkshire children's cancer charity, Candlelighters jointly fund the lab.

### Equipment

The Leeds neurosurgical team needed a specialised neurosurgical microscope to aid with the precision work involved in the excision of brain tumours at a cost of £20,000, this was another joint funding purchase with Candlelighters.

We recently purchased an iPad with specialised speech therapy software to be used by the Speech Therapy team in Leeds. The cost was £600. BTRS purchased a lightweight wheelchair for patients to use at short notice at a cost of £500.

## 2013 Will Be Our 10th Birthday!

February 2013 will see us celebrate the charity's 10th birthday marking the continuation of invaluable support and research for brain tumour patients, families and carers across Yorkshire. 2011 has been our best year to date and we aim to build on our positive progress in order to mark our first decade in style! Please continue your fantastic support and make sure you keep checking in on our website [www.btrs.org.uk](http://www.btrs.org.uk) for more details.

Join our **10th**  
**birthday**  
celebrations!

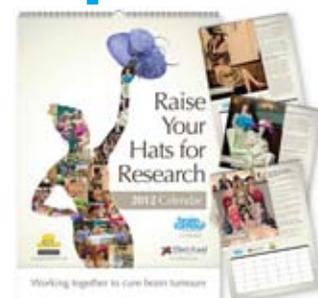
## Talk to a Parent

Is an initiative that will launch later in 2012 and will provide access to a network of parents who have first-hand experience of how terrifying it is to hear the words "your child has a brain tumour". The TTAP group of volunteers will be on hand to answer calls from 0900 to 2200, 7 days a week and provide a shoulder to cry on together with practical advice and support.



## Calendar Girl Update!

The 2012 Raise Your Hats for Research Calendar has been a great success, with the ladies selling hundreds of copies! The most sold was Helen Peaker (Miss March) with sales topping £1400, closely followed by Miss October Janet Dolan £1160 - both ladies will receive a bottle of Champagne in thanks for their sterling efforts!



# Fundraiser Stories

**Rosa Topley dragged her family and friends** over the Yorkshire 3 Peaks (right) on a stunning, hot day in July - Team Topley raised over £5,000!

In October, **Mark Harris dragged his family and friends** over the same Peaks, supported by his father in law Harry Maltby and Greggs bakers, the team raised £3,042!

**Jai Mistry and Matthew Hardill** went coast to coast across Scotland - they



Team Topley!

walked, ran, swam, kayaked and crawled across and raised a fantastic £2,500!

**The family and friends of Gareth Parr** raised almost £1,000 when they completed

the Lyke Wake Walk - a 40 mile trek across the North York Moors.



Long time supporter **Bob Clarke** (above) set out to walk literally thousands of miles in memory of his precious grandson, Callum when he set off to walk from Home to Rome in the summer. Sadly, Bob had to end his trip early due to illness, but still raised a magnificent £1,888.

**Margaret Ehrenberg** (below) raised over £1,000 when she ran an incredible 180 miles from Birmingham to Leeds in memory of her very good friend Colin Morath.



**Family and friends of Andrew Wilson** have raised over £8,000 through collections and a concert where Andrew played the drums at Colne Muni. Daughter Rachel Wilson was chief fundraiser and did an amazing job! Sadly Andrew passed away on Christmas day aged 57.

**Jamie Read** raised £843 through sales of his ever popular Baildon Calendar!

**Tom Brook** started to make his own jewellery and has hosted a number of parties which have become hugely successful raising over £1700!



**Gail Hammond and Peter Crane** (above) cycled from Lands End to John O'Groats and raised £3,395. Paul Bruce and a team of friends also cycled the LE2JOG route and raised £612! (photo to follow)

**Steve Pilmer's friends and family** have raised over £7,300 and held a number of fantastic events including a sponsored walk and Billy Pearce night at Horbury WMC. Steve suddenly passed away in November.

**Heather Coupland** continues her fundraising in Slaithwaite and has now raised almost £14,000 in memory of her husband Robert.

**Sharon Nicholson together with Darren and Tracey Longthorne** put on a fantastic Karaoke night and raised £2,850.

**Gaynor Stowe and her mum Dawn McPartland** raised £1,600 at their charity night.

## Contact:

BTRS c/o Howard House, Wagon Lane, Bingley, BD16 1WA  
Tel: 01943 870 770 | Mob: 0791 888 2816

Web: [www.btrs.org.uk](http://www.btrs.org.uk)  
Email: [contact@btrs.org.uk](mailto:contact@btrs.org.uk)

Reg. Charity No. 1095931

incorporating  
andrea's gift

andrea's gift  
brain tumour research and support

# Can you help?

*Could you help us to develop Brain Tumour Research and Support across Yorkshire?*

*You can do this in many different ways:*

- Organise a fundraising event, such as a coffee morning or a car boot sale.
- Take part in a sponsored event, such as our Yorkshire 3 Peaks event on Saturday 21st April 2012, one of the Jane Tomlinson 10k runs or join our annual bike ride or walks.
- Make a one off or monthly donation via Justgiving at [justgiving.com/btrs](http://justgiving.com/btrs), or set up a standing order at your bank, or send a cheque made payable to BTRS.
- Make us your 'Charity of the Year', this is an excellent way for organisations to offer valuable support throughout the year.
- Take part in our Wear a Hat campaign in March - 2012.
- Sell cards and calendars at Christmas.

For more information, contact Carol on 01943 870770 or email [contact@btrs.org.uk](mailto:contact@btrs.org.uk)

## Tax Free Giving with Gift Aid!

Increase the value of your donation by more than 25% and it won't cost you a penny!

As long as you are a UK taxpayer BTRS can claim back at least 25p for every £1 you give, at no extra cost to you. All you need to do is complete this form and return it to BTRS. Thank you.

First name: \_\_\_\_\_

Surname: \_\_\_\_\_

Address: \_\_\_\_\_

Postcode \_\_\_\_\_

Amount donated £ \_\_\_\_\_ . \_\_\_\_\_

I want all donations I have made since 6 April 2000 and all donations in the future to be Gift Aid until I notify you otherwise.

Signed \_\_\_\_\_ Date \_\_\_\_ / \_\_\_\_ / \_\_\_\_



To qualify for Gift Aid, the amount that you pay in income tax or capital gains tax must at least equal the amount we will claim in the tax year.

Please make cheques payable to:  
BTRS

Mail to:  
Howard House, Wagon Lane  
Bingley, BD16 1WA

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