

thank you
for caring
about us xxx



cwtch



Newsletter:
Spring / Summer 2011

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- What's hot at the shops...



tŷ hafan

www.tyhafan.org

Tŷ Hafan - the family hospice for young lives. St. Hilary Court, Copthorne Way, Culverhouse Cross, Cardiff CF5 6ES
Tel: 029 2067 2060 Fax: 029 2067 2061 Registered Charity No: 1047912. Tŷ Hafan® is a registered trade mark. (apri11)

welcome

Hi, my name is Anthony and I am dad to a wonderful little boy called Rhys.

Rhys is severely disabled and is unlikely to live into adulthood. He currently has no diagnosis but has an underlying neurological condition, severe epilepsy, chronic lung disease and global developmental delay. This may sound like a lot of medical jargon...but put simply it means Rhys needs round the clock care.

In 2007 we were referred to Tŷ Hafan and since then our lives have never been the same.

Tŷ Hafan has given us so much help both at the hospice and at home. They are a real support network for us. Our amazing family link worker has been there from day one. She comes to visit us at home or in hospital if Rhys is poorly and is on the end of the phone whenever we need her.

My family are massive football fans and with the help of Tŷ Hafan, Rhys has been able to achieve his dream of meeting the Manchester United squad. This was a proud moment I will never forget and that is what Tŷ Hafan is all about for me, creating memories.

As well as our visits to the hospice, Rhys has been able to enjoy the benefits of play therapy in the comfort of our own home. It really helps to stimulate Rhys as well as being great fun. We can borrow specialist toys for Rhys which would otherwise be very expensive and so we can carry on the fun with Rhys between visits.

Tŷ Hafan not only helps Rhys; our whole family benefits from its support.

Our second child Carys will be able to join in with the sibling activities when she gets older and she gets lots of attention and cuddles from all of the staff to make sure she loves Tŷ Hafan just as much as Rhys. My partner Natalie and I are able to relax and enjoy some quality time together safe in the knowledge that Rhys is being well looked after.

I really can't express how much Tŷ Hafan has improved every part of my family's life. What I can say is a massive thank you to each and every person that gives their time, money and support to Tŷ Hafan, it really does mean the world to me, Natalie, Rhys and Carys.

Pictured: From the left, Anthony, Rhys, Carys and Natalie.





the things you'll do

Coleg Glan Hafren's students have proved that you don't have to go to all the way to the jungle to experience weird and wonderful food. They truly tested their nerve at the Childcare and Education department's "Bushtucker Challenge" recently, to raise funds for local charities including Tŷ Hafan.

Six brave students and a team of staff were sponsored to eat a feast of frightful fancies, including sheep's eyes in beef jelly, chillies stuffed with worms, "surprise" pie, frogs spawn, cheese with maggots, giraffe tongue and honeycomb fish heads. Good on them we say!

dancing on ice

We're so proud to have the continuing support of Holiday on Ice Gala Nights.

Over the last 15 years, the ice-skating team has raised over £30,000 to help hundreds of families in Wales.

The donations from ticket sales and bucket collections by Tŷ Hafan volunteers has made a remarkable difference. This year's show was more successful than ever and our Tŷ Hafan Ambassadors Sheila and Jeff Davies were thrilled to receive the cheque from the skaters.

A huge thank you from all the families!



want to win up to £12,000?

Help the children and families further by signing up to receive your copy of Cwtch by email.

All you need to do is visit www.tyhafan.org/signup and leave your name and email address.

Emails are a much cheaper way for us to keep in touch with our supporters. We promise not to bombard your inbox; just send you all the best news, latest events and inspiring videos.

It's that simple and it only takes a minute.

What's more, as a way of saying thanks we will give you an entry into Crackerjackpot*, the weekly Tŷ Hafan Lottery draw, where you are in with a great chance of winning up to £12,000 or one of 80 cash prizes!

Please enter your details online by **Friday 20 May**, as the draw will be made on Friday 27 May and we want to be ringing **you** with the good news!

So what are you waiting for, get online now!

* You must be 16 or over. Each person will only be entered into one draw.



christmas sparkle in bath

Sam Smart from Tŷ Hafan's Family Support team describes the very popular annual "Mums' Bath Shopping Trip" which she has organised for the past few years.

Thanks to popular demand, in December last year I organised not one but two mums' shopping trips to Bath Christmas Market.

Anyone looking in on our coach trip from the outside would have seen a group of ladies having a fun day out in Bath, soaking up the Christmas spirit and shopping until they dropped. But the trip is about so much more than that.

Over the years at Tŷ Hafan we've had the privilege to meet so many wonderful, brave and inspirational women who devote their lives to caring for their very special children. Very often, the attention of these women is focused entirely on their child 24 hours a day, seven days a week and somehow "me-time" slips into the background.

Tŷ Hafan's annual coach trips are a chance to give something back to these special ladies. From the moment they board the coach until the moment we drop them off exhausted at the end of the day – the focus is them.

We don our silly hats, flashy earrings and trolley dolly aprons and we wait on the ladies hand and foot. Food and wine are served, goodie bags laden with gifts are given, quizzes and games are offered and this year we even had a Mamma Mia sing-along during the homeward journeys.

Although it's a ludicrously early start, all the ladies stayed lively and awake for the whole journey to Bath and home again afterwards. Each time I grabbed the microphone to ask "what's it all about ladies?" I was met with the rousing response "...me, me, me" (well done girls!).

There are very few people who truly understand the lives of these women: the highs and lows, hopes and fears, joys and sadness are hard to imagine. All the mums on the trip seemed to understand that, even during fun times like the coach trip, laughter may turn into tears, they may need a sympathetic hug or some time out to help get through the day. This is the bond that unites these women.

I'd like to say a big thank you to the 94 ladies who came along with us this year. I'm already being asked about the next trip and I'm really looking forward to it – it's a real highlight in my year.

Sam Smart
Family Support worker
Tŷ Hafan

watch the video...

See the fun that was had by visiting:
www.tyhafan.org/mums-coach-trip

You can see footage of
Tŷ Hafan's events at:
www.tyhafan.org/youtube

Definitely a good watch!



what's hot at the shops...



It's been a busy and exciting few months for Tŷ Hafan shops! A big thank you to everyone who's donated items or popped in to a shop.

Our newest shop opened just before Christmas in Queen Street, Neath, and has had lots of visitors since then – pop along and have a look!

makeover magic

We've also given our shops in Caerphilly, Cwmbran, Pontypridd and Talbot Green a fresh new look, with lots of positive feedback from customers and our lovely shop teams.

They're looking fantastic and you will be amazed at how many great things there are to buy – from clothes and jewellery to household ornaments and CDs.



bring us your goodies!

We're always grateful for your unwanted, good quality clothing and household items. Why not have a clear out today and bring them to your local Tŷ Hafan shop? We'll be really pleased to see you and every bit helps.

Find out where your nearest shop is:

www.tyhafan.org/locations
029 2067 2060



a little extra goes a long way

Did you know that when you take your unwanted goodies to your nearest Tŷ Hafan shop, we can claim an additional 25p from HM Revenue for every £1 that we raise by selling your donated items?

If you are a UK registered taxpayer all you need to do is sign a Gift Aid declaration so your donations will go even further to help provide care for families across Wales.

So make sure that you ask about Gift Aid next time you make a donation! Thanks!

giftaid it

it's all down to you

Well, it all began with a wish list in Summer 2009
Lots of planning and preparation and things would work out just fine.
Link workers, playleader and administrators considering Rhiannon's request
To see a show in London – Wicked – the one she liked best.

So, on 26 March we boarded the transporting bus,
Just a few hiccups with seating, but this was changed without too much fuss.
Our drivers, Clive and John came as part of the team,
With Alison and Sarah, Mum and sister, Angharad to help make Rhiannon's dream.

The M4 was pretty clear only stopping off for doughnuts, coffee and toilets,
But hitting London, we got caught up in traffic heading for the riots,
(Oh, no, sorry – that should have said "protests", but it didn't rhyme and there were riots! Honestly!)

We arrived at our destination, just ten minutes late for the show,
But staff at the Victoria Apollo said "No, No, No!"
No, we couldn't get to see the show because we hadn't arrived in time,
How disappointed we all were that things didn't turn out fine,

But wait, was this a good witch from the Wicked show?
No, Jenna, the deputy manager with her face all-a-glow,
She was delighted to inform us that we could return much later,
And see the evening performance in their lovely theatre.

Phonecalls, further planning and permission was sought,
To stay the extra hours, for a while it was quite fraught.
The bus drivers were kind enough to extend their working day,
Sarah and Alison would be sure to find a way.

So rearrangements made to stay a while, we got to see the leads,
Louise and Rachel, were very happy to please.
The two lovely ladies posed with us for photographs,
With pens and programmes at the ready, we even got their autographs.

More coffee, cakes and chocolate sweets
To fill the hours before our real treat.

Finally, the platform lift was waiting outside,
For Two wheelchairs and occupants to get inside,
The theatre where it was all to take place,
Oooohhhh, if you could only see Rhiannon's face!

Dragons, Monkeys, Spells galore,
Only left us wanting more,
Dancing, costumes and singing to astound,
Made us feel we'd left the ground.

Rachel and Louise, the stars gave us a special wave farewell,
To see us on our way down the stairwell,
Back to the bus, and the long journey back down the motorway,
Back to Tŷ Hafan to finish our stay.

It was such a special trip, not possible you see,
With out all the planning and the crucial money,
For I know it costs more than a few pounds to make a wish come true,
It costs more like hundreds, and a lot of good will too,

So I say a very big thank you to everyone who cares enough,
And is giving to the hospice, even when times are tough,
For without your donations my daughter's life would be,
Just that little bit sadder, I'm sure you'd agree.

**To see her laugh and smile all day, excited by her wish made true,
Has all been down to you.**

God bless, love Debbie x

WICKED
THE UNTOLD STORY OF THE WITCHES OF OZ

a cracker of a visit from sophie

Christmas is such a special time for families at Tŷ Hafan and they were over the moon (and the rainbow!) to get a visit from Sophie Evans this year – who will be playing Dorothy in Andrew Lloyd Webber's West End musical "The Wizard of Oz".

Sophie took time out of her busy schedule to come and wish everyone at Tŷ Hafan Merry Christmas. She spent the afternoon meeting some of the children and families and was

keen to learn all about the work Tŷ Hafan does to make a difference to their lives, both at Tŷ Hafan and in their homes and communities.



a fantastic time for footie fans

As well as having lots of attention from Sophie, we played host to a visit from the entire Cardiff City football squad. Manager Dave Jones and his boys joined families and staff

for the Carol Concert we held in December and afterwards they spent time chatting to some of our avid football fans – who were thrilled to meet some of their heroes.



it's behind you!

We had so much fun doing our yearly pantos this Christmas, with twice weekly performances given by the staff.

We did an action-packed production of Dickens' classic "A Christmas Carol" with a special guest appearance by "Bob Marley", which all the children loved.

Pictured: Tŷ Hafan staff showcasing their first-class acting skills.



always there

Rhys was only six when his sister Bethan died at the Tŷ Hafan hospice.

Bethan was born with severe congenital brain damage leaving her with profound disabilities and needing constant care which resulted in her mum Clare having to leave her job.

The family from Swansea were referred to Tŷ Hafan in 2005 and at first naturally felt very apprehensive about the hospice.

"I clearly remember bringing Bethan to look around the hospice prior to her first visit" recalls Clare. "It was not what we expected at all."

"There was no suggestion that this

was where people came to die, but rather where they came to live. Tŷ Hafan quickly became the only place where we could leave Bethan to be cared for and take time to charge our batteries, get some sleep and spend quality time with Rhys.

"At the same time we were made to feel that the hospice was somewhere that cared for all of us, not just Bethan. Rhys still reminds me that he went there first!"

Rhys quickly became a regular at the organised sibling group events. Everyone was in the similar situation of having a life-limited brother or sister who needed a lot of their parent's care and attention.

Lynne Doyle, Sibling Support worker, arranged groups especially for bereaved siblings which Rhys joined after the death of Bethan in January 2007.

"When you have a severely disabled child you spend most of your time surrounded by professionals. We had staff coming in to help care for Bethan five or six days a week. After she died this suddenly stopped but Tŷ Hafan continued to give us their support.

"Rhys has said on more than one occasion, following invites to sibling days and parties, that at least Tŷ Hafan hasn't forgotten about him."

As if we would!

Clare is now one of Tŷ Hafan's Ambassadors playing a valuable role attending cheque presentations and giving talks in the community.



Pictured: Rhys (far left at the front) with just a small group of his Tŷ Hafan friends at Sibling Day.

where does your money go?

An hour of **specialised advice on life-limiting conditions** for a family living with the unbearable reality their child will die before adulthood **costs...**

£21



A whole day of **support for three families in their own homes**, giving parents of life-limited children and young people the help they need to tackle their daily battles **costs...**

£441



How you can help...

Donate at www.tyhafan.org
or
Text **CARE** to **70800**

You will be charged £5 plus your standard network rate. Tŷ Hafan will receive a minimum of £4.40 from each SMS sent.

£42

could pay for **two hours care for a life-limited child or young person** so mum and dad can have precious time giving their other children the attention they often miss out on.



Music therapy for a child or young person in their family home, **their own bedroom** or lounge costs...

£120



£1956

will allow a family a **weekend of short break care** at our family hospice for young lives. This includes all their accommodation, food and drink and the **24 hour specialised nursing care** their life-limited child needs.



Whilst we try hard to ensure your payment will go to the area of support that you have chosen, we may not always be able to allocate funds in this way due to over-subscription or demand. Any over-subscription or surplus from your gift, after all costs of your chosen area of support have been met, will be used for the charitable purposes of Tŷ Hafan and will be spent for the benefit of the children, young people and families using our care services. Please be assured every gift will continue our care provision programme and assist in making the lives of the children and young people as comfortable and enjoyable as possible.

right side of the law

Congratulations and thank you to everyone at Convey Law for their fantastic support throughout 2010.

Not only did they introduce a Free Legal Fee competition to their clients – raising over £24,000 for Tŷ Hafan – but every month staff also held a dress-down day with everyone contributing £2 to wear jeans or their favourite casual clothes.

Convey Law also held fundraising parties and 20 members of the firm

took part in the Tŷ Hafan Midnight Sleep Walk. One member of staff, Tracey Havelot, even took part in the London Marathon, contributing to a staff total of over £3,500.

Altogether, the team at Convey Law raised a whopping £28,000!

**On behalf of the families,
thank you Convey Law.**



hero of the match

Cardiff City's new training facility, the House of Sport, was more like Gotham City as 12 first team players turned into 'superheroes' to play a six-a-side charity game in support of Tŷ Hafan.

Families from Tŷ Hafan were delighted to see their sporting heroes take on their alter egos, and two of the children acted as mascots.

Without a doubt, man of the match was Kevin 'Danger Mouse' McNaughton who scored twice.

Danger Mouse was ably assisted by teammates Chris 'Robin' Burke and David 'Zorro' Marshall.

Tŷ Hafan would like to thank everyone at Cardiff City for all their hard work in organising this event.

sports star for lunch

On Thursday 5 May an exciting event is coming to Cardiff City Stadium. Hosted by Tŷ Hafan's Corporate Support Group, the Sporting Lunch is a celebration of Wales' sportsmen and women.

Whether you are looking to do some informal networking or simply enjoy an afternoon with your favourite Welsh sporting stars, at only £250 for a table of ten this event is not to be missed.

If you'd like to know more, get in touch with **Diane Stringer** on **029 2067 2080** or **diane.stringer@tyhafan.org**



a chance to win, a chance to care

Crackerjackpot is a fantastic way to support hundreds of life-limited children, young people and their families. It costs **£1 a week** to join and be in with **a chance of winning £2,000 every Friday** or **up to £12,000** in the rollover.

We would like to say **a big thank you** on behalf of the children, young people and families for your continued support.

You're giving them a helping hand, a shoulder to cry on and a whole family support network when the unthinkable happens.



Here's how you can find out more about Crackerjackpot...

Text **JACKPOT** to **70800**



congratulations ann and winifred

For the first time since its launch in November 2009, the Crackerjackpot rollover reached its maximum amount of £12,000. The lucky winner was Mrs Ann Williams from Fforestfach in Swansea who couldn't believe the news when she heard.

When we asked Ann what she would be spending the money on she said "I'm due to have a second hip replacement soon, so we're planning on putting a downstairs bathroom in

to make life easier for us after the operation. We also have a granddaughter and two more on the way, so there will be presents all round!"

Another lucky lady was Winifred Lang from Beddau, who won a brand new Suzuki Splash in our Christmas Prize Draw. She almost didn't buy her winning ticket, but after reading about Bradley in our last edition of Cwtch, Winifred was convinced her money would make a real difference.

Pictured: Ann and her husband, with Tŷ Hafan's Lottery Marketing Officer.



Don't forget you could be £12,000 richer if you receive your next copy of Cwtch by email.

See page five for more details.

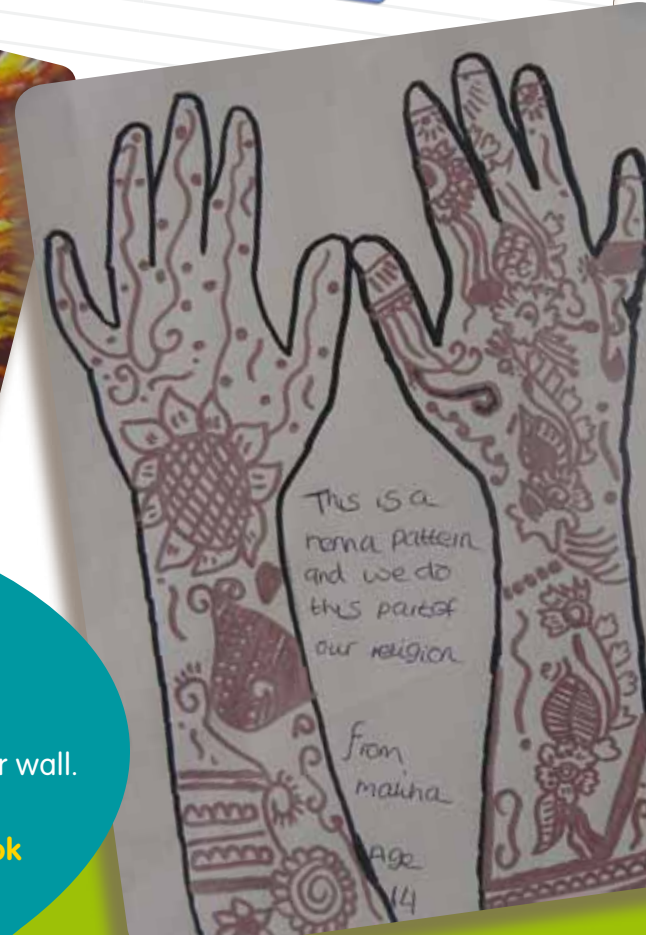


cwutch corner



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and help us spread the word.

[www.twitter.com/
tyhafan](http://www.twitter.com/tyhafan)



"Like" us on Facebook
and post a message on our wall.
We'd love to hear from you!

www.tyhafan.org/facebook

sleep walk for tŷ hafan

Round up the girls, bring out your best pyjamas and come along to one of our Midnight Sleep Walks!

So many mums of life-limited children, often with many complex needs, rarely get a full night's sleep which can put an enormous strain on their health and family life. To celebrate the dedication of these mums we're giving up one night's sleep to raise vital funds so these mum get a well-earned rest at Tŷ Hafan – so why don't you join us and show your support?

There are three Midnight Sleep Walks this year: in Swansea, Cardiff and the old Severn Bridge (M48). All ladies are welcome – from girls to grannies. All you need to do is register online, get your pyjamas on and come along on the night.



There will be lots of fun things to do before the walk begins, like games, competitions, manicures, warm-up sessions and more. And every lady will receive a free t-shirt, flashing bunny ears, glowsticks, a commemorative medal and be greeted by a piping hot cuppa at the end.

You can get your fellas involved too – we'll need midnight marshalls on the night to help with all sorts of things. They can join in the fun too!

Register now...
www.midnightsleepwalk.co.uk

knock out!

Our first ever 'It's a Knockout' in 2010 was such a roaring success that we're bringing back the fun and games this year.

There will be lots of soapy water and loads of laughs as teams of up to ten people go head-to-head on giant inflatables. The games are designed so it's not just the fastest and fittest who always win. Thought and skill are definitely required.

'It's a Knockout' is the perfect opportunity for friends, family and work colleagues to get together, have lots of fun and raise loads of money for Tŷ Hafan. We're looking for around 40-50 teams to take part. It could be you and a group of friends, your colleagues or members of a club you go to.

What are you waiting for? Get your team together, pick that all important team name and register today if you think you've got what it takes to beat last year's "It's a Knockout" champions.



tŷ hafan events 2011

Friday 6 May
Friday 13 May
Friday 20 May

Midnight sleep walk, Swansea (seven miles)
Midnight sleep walk, Cardiff (eight miles)
Midnight sleep walk, M48 Severn Bridge (six miles)

Saturday 11 June
Sunday 24 July
Sunday 4 September

Welsh Peaks Challenge
It's a Knockout
Taff Trail Cycle Challenge

aaron's story

Eleven year old Aaron was referred to Tŷ Hafan in the first year of his life in 2000 having been diagnosed with McCune Albright Syndrome.

The condition known as MAS is a rare genetic disorder affecting the bones and skin pigmentation. Aaron has also been diagnosed with autism.

Due to the affects of Aaron's condition, he is unable to walk, has little speech and cognitive understanding and needs constant 24 hour care. As he can't express the pain he feels like another child may, Aaron can cause harm to himself and others when experiencing stress or distress. Needless to say his family has found trying to cope with these issues a constant daily battle.

The family recently reached a crisis point. They were finding it difficult to cope with Aaron at home and their own health was at risk.

Tŷ Hafan has helped Aaron's family to draw on their own strengths and resilience, allowing them space to pull through the difficult issues. Their tailor made care package has changed their lifestyle for the better. **They're a family again, enjoying the simple stuff of life. Like we all deserve to do.**

Pictured: Aaron spending time at the Tŷ Hafan hospice.



Text CARE to 70800 now!
Make an instant difference to hundreds of families, just like Aaron's.

You will be charged £5 plus your standard network rate. Tŷ Hafan will receive a minimum of £4.40 from each message sent.

care for a girly night out?



tŷ hafan

Round up the girls, put on your pyjamas and give up one night's sleep to raise money in support of hundreds of mums with life-limited children.

Register now...

www.midnightsleepwalk.co.uk

friday 6 may

the LC
swansea

friday 13 may

millennium stadium
cardiff

friday 20 may

M48 severn
bridge



Kindly sponsored by...

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