

newsletter

Teen Spirit



Jessie May nurses care for children of all ages from tiny babies to teenagers. Here is the story of 13-year-old, sports mad Ryan, who is just one of the teenagers currently on the Jessie May Trust caseload

Like a lot of teenagers Ryan Abrahams loves his PlayStation and is a master at the Call of Duty and Fifa football games. He is a keen sportsman, enjoying football and cricket and he loves R&B music. He is a fan of South Park and The Simpsons and enjoys racing his remote controlled car with his Dad, Mark along Weston Super Mare beach when time and weather allow.

However Ryan, 13 was born with the Spinal Muscular Atrophy (SMA), a condition that affects the nerves in an area of the spinal cord which means that muscles can't be used and become wasted or atrophied. Ryan therefore relies on a motorized wheelchair for his independence but is certainly making every effort to live life to the full.

Ryan attends mainstream school and is an active year 8 student. Like most teenagers however Ryan is not necessarily a fan of school. When asked what he liked best about school, he replies after much thought: "Well, Monday 2.15pm, Tuesday, Wednesday & Friday 2.45pm and Thursdays 3.15pm!" Needless to say these are the times that the school day ends and Ryan can go home to be re-united with his PlayStation and his two dogs Lucky & Star. Ryan's Mother, Mary says: "When Ryan was born he was like any other baby, beautiful and made our family complete. For the first 6 months of his life everything was perfect. Then we realised something was not quite right and asked our GP for help. After many tests we were then told when Ryan was 9 months old that he had a rare condition that we had never heard of before. Our World just fell apart."

Ryan Abrahams with his Football Player of the Year trophy



Ryan with his dog Star

The family joined The Jessie May Trust caseload in 1997, and were one of the first families to receive our support. Mary & Mark receive 'on-demand' respite visits from The Jessie May Trust, which allow them to go out for a while, or take advantage of a spur of the moment invitation, which many of us take for granted. This allows Mark & Mary to spend quality time together and not to have to worry whether the venue is disabled friendly: "We do not have any help other than the Jessie May Trust and they are our lifeline."

Despite his difficulties Ryan is an inspiration with his sunny disposition, cheeky smile and determination to join in. He is, according to Mary the class comedian, and is sure to keep everyone entertained! Ryan has recently been selected to represent South Gloucestershire in the table top cricket championships at Lord's in May. He is also a keen football fan,

with a preference for Manchester United and in particular Ronaldo. Each Friday evening his parents drive him to Birmingham for his football training sessions at Villa Park, home of Aston Villa. Ryan was awarded player of the year in 2007/2008 and is proud to show off his trophy that adorns the shelf alongside a glass rose bowl awarded for a special determination award.

Ryan is a season ticket holder for Bristol City FC, having swapped allegiance after sitting next to John Laycock, former chief executive at an awards dinner. After promising him a signed shirt the deal was done, and now come wind or rain Ryan will be on the touchline cheering his team on.

Ryan's story is one of determination, courage and a positive attitude to life. Thanks to the support of The Jessie May Trust Ryan's family can make the very best of their precious time together.

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Jessie May needs you!

We are now over 2 years into our Precious Time Appeal with only a few months left to reach our target. However we are pleased to announce that we are well on the way to reaching £1.4million and at the time of going to press we had reached £1.2million! That said we still do have a way to go. **We have £200,000 to raise in two and a half months** – that's an average of £20,000 a week! This may seem a lot but **WE CAN DO IT!** We have many exciting things planned in the coming months which should help us along the way but please dig deep if you can. Today - the value of supporting terminally ill children at home seems more important than ever and we couldn't do it without the generosity of kind donors like you. With a little help from everyone we should get there and when we do, we will be able to help many more families in the area and provide more visits to the children on our current case load who so desperately need it.

Since the beginning of the appeal our supporters have done many things to help us raise funds and we sincerely thank you for that from the bottom of our hearts. You have run half marathons, organised collections, held golf days, jumped out of planes! - the list is endless. We have also had some tremendous support from grant making trusts and many local businesses. All of the above have taken us closer to our Appeal target and will thus enable us to help more local families and give them all the support they need to care for their child at home.

Using the funds raised so far towards our Precious Time Appeal we have recruited 3 additional specialist nurses and a nursery nurse to the core Care Team and have provided over 9800 hours care to families. This is more hours than we have ever provided before and that is down to the sheer generosity of supporters like you. We really cannot thank you enough. 23 families have joined our caseload over the last 2 years but we know that there are more that need our help. We have recently started some outreach and partnership working with health professionals and our nurses are regularly liaising

with families and staff at local hospitals to ensure that all families who may need our help are fully aware of the services we offer.

To increase our caseload further however, we need more funding and we certainly cannot stop once we have reached our Precious Time Appeal target. Once the Appeal is over we still need to raise just as much to keep our valuable and unique service operating at the capacity which our families have become accustomed. The families on our caseload want and need more hours of service and this added to the families we still need to reach, we need to continue raising funds at the same level as we have been so fortunate to be able to do over the last few years.

Every penny really does count. Each £9,500 raised is enough to care for one child and their family for a whole year and each £30,000 raised could fund a new Jessie May Nurse.

Thank you once again if you have donated towards our Precious Time Appeal, we are exceptionally grateful whatever the amount. If however you are reading this newsletter and considering making a donation and have not yet done so, please help us in our vision of ensuring that by 2012, every local family with a terminally ill child has the level of specialist support at home that they need.



Help us to reach our target, call us now to make a difference! 0117 961 6840



Runners in Team Jessie May in the Bath Half Marathon 2009
Runners have raised over £52,500 during the Precious Time Appeal through running in marathons, half marathons and 10K runs.



Nursing care at home for children with a terminal illness



Kingsfield School Christmas Carol Concert 2009 in aid of The Jessie May Trust
By taking part in dress down days, carol concerts, sponsored runs and selling cakes, local schools have raised nearly £10,000 towards the Precious Time Appeal.

The Jessie May Trust would like to thank all our fundraisers for your gifts both large and small and for your continued support



Community groups and associations have donated over £123,500 towards the appeal since 2007.

The Mayflower Branch of the Foresters have supported the charity for over 8 years, and have raised over £18,000 towards the appeal since 2007.

Through asking for donations instead of gifts, weddings and birthdays, fundraisers have raised £6,500 to the Precious Time Appeal.

Mr and Mrs Clements asked friends and family for donations at their recent Golden Wedding Anniversary and raised a fantastic £612.00!



To support The Jessie May Trust call 0117 9616840 or visit www.jessiemaytrust.org.uk

FRIPP gets an update

Families who have a child on the Jessie May Trust (JMT) caseload, will be familiar with the FRIPP (Framework for Respite in Partnership with Parents and Carers). This is the tool that we developed in 2001 to allocate the amount of respite care that we offer to each family in the fairest way possible.

Using FRIPP gives parents and carers the opportunity to discuss what is happening in the lives of the whole family and how this affects the care they are able to give to their often severely disabled child. The score they give themselves determines the frequency of visits offered to the family.

We have been fortunate to have recently commissioned an independent evaluation of the FRIPP tool in order to see if the tool is still relevant and fair to our families.

The research has concluded that the FRIPP documentation is fulfilling its' purpose of making respite allocation transparent and fair for all the families on the JMT caseload, although a few modifications could make it more useful.

The JMT care team are looking forward to studying the report in detail and working in partnership with the families using the service to implement recommendations. This will make the tool more relevant to our current families and continue to keep the allocation of our resources as fair and transparent as we can make them.



Dr Nicola Eaton

My Name is Liz Lewington and I have been Care Team Manager at The Jessie May Trust since July 2001. Although much of my role can be office based, the times that I really cherish are when I have the opportunity to leave the paper work behind and visit the children, young people and families on our case load.

A visit may be to renew the Care Agreement contract for the next year or very occasionally (for me) a specialist respite visit. During these respite visits the children's nurse or nursery nurse needs to make sure that all the child's medical needs are taken care of. However, we can also have a fun time with the child or young person on the caseload if they are well enough. We may listen to music, read a story or go out for a walk, which is particularly lovely this time of year with the spring flowers and the lovely sunshine.



Liz Lewington
Care Team Manager

I would like to say a big thank-you to all the children, young people and families on our case load. Thank you for being so lovely and making all the staff at The Jessie May Trust, including myself so welcome in your homes so that we can provide our vital service. Since 1st April 2008, up to the end of January 2009, The Jessie May Trust Care Team have provided a staggering 4,145 hours of care. Therefore I would also like to say a big thank-you from me to our wonderful Care Team and Extended Team who have worked so hard to provide these hours and special care.

We know that there are more children in the area who would benefit from our service, so to help 'spread the word' to new families and health professionals, we have produced a new leaflet called 'A Guide for Families'. This leaflet (pictured) includes photos of some of the very special children and families on our caseload and gives all the details of our service.

The leaflet will provide families and professionals with more information about The Jessie May Trust, explain how to reach us and encourage them to find out more, thus helping us to help more children and young people.

Thank you once again to our nurses, families and of course our supporters.

Best wishes.



We're off to a flying start. Volunteers needed!!

Against stiff competition we were selected by Bristol International Airport as their charity of the year. We now need your help to make this as much of a success as we can and reach new heights in the provision of care to our families.

We are going to be undertaking a series of airport terminal collections to take advantage of all the passengers departing and arriving. We launched on Saturday March 21st, and so far we have raised over £4,000. We will be collecting every Saturday and every Monday from 8am-6pm throughout the rest of the year, so we really are in it for the long-haul and need your help!

16,000 customers pass through the terminals each month so we really can make a difference. We are fortunate to have collection boxes that are placed at all 56 till points throughout the airport.

Ideally we are looking for collectors who can do a minimum of just two hours, on a Saturday or a Monday. As we have access to the terminal at all times if you are a club or group that can do any other day then we really want to hear from you too!

With 250 employees and access to a further 3000 personnel then we have a real opportunity to raise our profile towards the final push for our Precious Time Appeal.

Please call the fundraising team on 0117 961 6840 who are waiting for your call.

THE JESSIE MAY OFFICE TEAM



BACK ROW L-R: SANDIE CONSTABLE, RUTH BUTCHER, TINA LEDDRA, NILAY NERGIZ, JACKIE ENGLISH, JAYNE SHORT, SARAH WATTS.

MIDDLE ROW L-R: GEORGETTE LESTER, FIONA PEARCE, LIZ LEWINGTON, KATH BAILEY, HELEN WILLIAMS, MELANIE BALL.

FRONT ROW: L-R: CHRIS ROYS, KATE BUDDERY

The Jessie May Trust is to benefit from a West Country racing driver's fundraising support this year. Roger Orgee, who in 2006 was awarded one of the biggest prizes in Motorsport, a BMW scholarship, is competing in the 2009 Formula Ford Championships at Castle Combe this season. Roger and the team are offering you a chance to be part of this, by offering a package giving branding on both car and driver as well as a hospitality option for you to entertain clients or employees during the weekend of Saturday 08th & Sunday 09th August, which is the Summer Racing Festival at Castle Combe. The Jessie May Trust will benefit by receiving 50% of the funding that the team receive. If you are interested in supporting Roger and in turn The Jessie May Trust please contact Roger Orgee senior on 0778 2201489.



To support The Jessie May Trust call 0117 9616840 or visit www.jessiemaytrust.org.uk

What's On

Friday 1st May 2009

The Institute of Legal Executives (Bristol and Bath) Spring Ball in aid of The Jessie May Trust is taking place at the Marriott Hotel, Castle Green from 7pm until late. Tickets cost £35. Please contact Sarah Cleave on 0845 4156843 or e-mail sarah.cleave@bondpearce.com for more information.

Sunday 10th May 2009

Tickenham Sponsored Walk in aid of The Jessie May Trust and MS Therapy Centre. Organised by the Rotary Club of Nailsea and Backwell, there will be a choice of three distances, all starting and finishing at Tickenham Village Hall. Call John Glason on 01275 463969 for details and sponsorship forms, or email glason@tiscali.co.uk.

Sunday 10th May 2009

Do you have your own place in this year's Bristol 10K? If so, join Team Jessie May and help raise valuable funds for our service. *Please contact Kate in the Fundraising Team for more information.*



Wednesday 13th May 2009

Fundraising 'At Home' afternoon in Coalpit Heath, organised by supporter, Celia Morrish. Includes bring and buy sale, raffle and refreshments. **10am-12noon and 2pm-4pm.** Contact Celia on 01454 250716 for more information.

Saturday 16th May 2009

Clevedon Consti Club Casino Night. 7.30pm for 8pm start. Tickets cost £10.50 to include casino entertainment and hot Italian supper. *For tickets please call the club on 01275 872834.*

Friday 5th June 2009

Join local teams at the annual Bristol and Clifton Golf Club Golf Day, this year in aid of The Jessie May Trust. Two shotgun starts. Entrance into the morning at 8.30am competition now available. A modest price of £120 for a team of 4 players to include food and prizes and the opportunity to play on one of the most prestigious courses in Bristol. *To enter a team, please contact Robert Skinner on 0117 9238239 or 0117 9624117.*

Tuesday 23rd June 2009

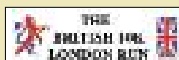
Jump for Jessie May! Skydive with the Red Devils. Dunkerswell Airfield, Taunton. *Sign up for this once in a lifetime opportunity by contacting the Fundraising Team.*

Sunday 28th June 2009

The Bristol Chamber Choir Lunchtime Concert in aid of The Jessie May Trust. This fantastic concert is to be held at St George's, Brandon Hill, one of Britain's leading concert halls famous for its exceptionally fine acoustics. *For tickets, please contact Sue Merriman on 01275 464143.*

Sunday 12th July 2009

London 10K. Gold bond places are still available from the fundraising team in this fantastic event running right through the capital's city centre.



Sunday 21st July 2009

Bristol's Biggest Bike Ride. Get on your bike and ride for Jessie May. The event is free to enter and with routes from 9 to 38 miles, there is something for the whole family. *Please contact the fundraising team for an information pack.*



Saturday and Sunday 7th-8th August 2009

Collection at Castle Combe Circuit at Summer Racing Festival in aid of The Jessie May Trust. Volunteers needed to shake a bucket, free passes to Formula Ford Championship included.

Please contact Kate in the fundraising team

Wednesday 12th August 2009

Fundraising 'At Home' afternoon in Westbury-on-Trym, organised by supporter, Dorothy Willis. Includes bring and buy sale, raffle and refreshments. From 2.30pm. *Contact Celia on 01454 250716 for more information.*

Saturday 29th August 2009

Kingstock 2009. King's Head, Bedminster. Enjoy an afternoon of live music and drinks in this fantastic pub in Bedminster Down, with funds raised on the day to The Jessie May Trust. *For more information, please contact Paul on 0117 964 3582*

Sunday 6th September 2009

Gold Bond places are available in the Bristol Half Marathon 2009 as part of Team Jessie May. *Contact the Fundraising Team to sign up today.*



Jump for Jessie May! with the Red Devils in 2009

Jessie May Fundraisers are flying high this summer as they take part in the first set of Jump for Jessie May skydives on Thursday 28th May, and Tuesday 23rd June.

And this year's jumps have an added twist as we take to the skies with the world famous parachute display team, The Red Devils. Participants will join The Jessie May Trust team at the Netheravon Airfield in Salisbury, or the Dunkerswell Airfield in Taunton, where they will be briefed by the Red Devils team before setting off for a 15 minute flight over the rolling English countryside.



At 2 miles up, they will exit the aircraft and experience a thrilling 45-seconds of freefall as they reach speeds in excess of 120mph freefalling 12,000 feet through the air. At about 5000ft their very own Red Devils instructor will open the parachute and they will begin their 5 minute scenic parachute descent expertly guided down to the drop zone, landing to the cheers of friends, family and the rest of The Jessie May Trust team.

Leanne White from the Victoria Square Hotel in Clifton has already signed up to take part. She says 'I've always wanted to do a skydive, so when I heard about this one with the Red Devils, I jumped at the chance to raise funds for Jessie May, our nominated charity. It will be the high point in a series of fundraising events we are planning. I just hope I'm still as eager in May!'

Father and daughter, Bob and Emma Griffin have also signed up. Bob says 'My daughter, Emma, and I had talked about doing something like a parachute jump, and when I heard about the event we thought it would be a great way to do something we had only talked about. Now, not only are we able to fulfill a dream but it gives us another opportunity to raise much needed money for a very good cause.'

CLICK AND JUMP .CO.UK

If you would like to take part in a jump for The Jessie May Trust, then please give Kate in the Fundraising Team a call on 0117 961 6840 or e-mail kate.buddery@jessiemaytrust.org.uk.

The May jump has sold out, but places are still available on Tuesday 23rd June 2009.



If you would prefer not to receive this newsletter in future, please let us know so that we can update our records.
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