

30 YEARS OF CARE

THE SUSSEX
Snowdrop
Nursing care at home for local children
with life threatening or terminal illnesses **TRUST**



Newsletter

Autumn 2023



This is a lovely picture of Beau with his mum and brother Harrison watching lambs being born at a private farm in Lurgashall. Beau was born prematurely at 29.5 weeks old with an exceptionally rare condition. He has CCHS - Congenital Central Hypoventilation Syndrome - plus a chronic

lung disease, Hirschsprung's Disease and is on tracheostomy ventilation 24/7. The family must take a trolley load of equipment with them wherever they go, but it doesn't stop them having great family time together.

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www.thesussexsnowdroptrust.com

Happier Times

Mum, Eloise explains, "To go out it takes around 15 mins to pack the car, and then unload the car. I squeeze in: a double buggy, 2 ventilators, suction machine & catheters, 'trachie' box and the nappy bag which contains a nebuliser kit, sats machine and syringes & fluids! And not forgetting the usual baby items such as spare clothes, nappies, wipes and snacks... and then baby Beau in a car seat in the front!"

As a charity, we think it is important to celebrate happier times together, so we organise a series of events where this is possible. This Spring, the Snowdrop families were invited to a local farm, which enabled the children to experience baby lambs being born up close, collect eggs from the chicken coop and eat wonderful homemade cakes from a traditional farmhouse kitchen baked by many village friends. The families were also able to explore the grounds with an Easter egg hunt and went home with a large chocolate egg thanks to donations from the Nuffield Gym and Balfour Beatty.

The Collins family commented -

"As a family, Snowdrop brings outings of joy for us. It allows us to forget about life's pressures and enjoy each other, making memories. We thoroughly enjoyed the lambing over Easter, Jude got involved too. Cake and chocolate were provided... who doesn't love this!"

Amy Collins goes onto say; "We have been super lucky and are very grateful for these opportunities given to us. Ice-skating in Bognor was brilliant, and Drusilla's was awesome. We even stayed at a youth hostel due to travelling, it broke up the journey and allowed us to relax and enjoy. Snowdrop you are truly amazing."



Eloise with Beau and Harrison

Collins family

Great Experiences

The Trust also provides family days out in the summer which are very much appreciated by our Snowdrop families. This is a chance to bring the family together in a relaxed atmosphere. Families enjoyed trips to Drusillas, Paultons Park, Chessington, Marwell Zoo, Cineworld, Fishers Farm etc. We also provide vouchers to help with petrol costs and food for picnics.

The Supercar Track Day at the iconic Goodwood Motor Circuit is organised by Saywell International and is open to everyone to attend. The charity is fortunate to benefit from fundraising at this special Supercar Day which is hosted by Peter Saywell who loves and collects Supercars. Pictured here is Samuel who picked out the blue McLaren with Peter and had the thrill of being driven round the track. Attendees were able to see some incredible Supercars in action on the track. The line up included the Ferrari 812 Competizione, Porsche 918 GT3RS, McLaren Senna, McLaren 765LT, various Aston Martins, Ariel Atom and the Pagani Zonda. The owners of the cars and the drivers donated to the charity, as well as the attendees on the day who enjoyed the 'Spot the Super Car' game, toy tombola, and races on the South Downs Slot cars. The day generated a record sum of £11,643.19. Whilst this day is open to everyone, it is very special when we capture moments that mean so much to Snowdrop families.

Samuel said of his exciting day; "Mummy I will never forget that!"



Peter Saywell with Samuel

Festive Fun!

The Christmas Party at Butlins is loved by so many and the Snowdrop families really look forward to this memorable event. Last year, 40 families enjoyed a lunch, musical entertainment, a family photo to take home, presents and a visit to Father Christmas' grotto. Butlins make the families feel very special - including a visit from the giant bears Billy and Bonnie, and the chance to use the rides at the park too.

In January, Snowdrop families have the opportunity to experience ice skating in Bognor, thanks to the Coles family who provide a private hour of skating for the charity so the children can enjoy the freedom and excitement of the ice to themselves.

Just imagine spending your time travelling back and forth taking your child to the hospital in Southampton, Chichester and even London. The endless waiting by the hospital bed, keeping your child calm as you wait for further tests. The reality of having a child diagnosed with a life threatening or terminal illness is a lot of



Di and the Coles family



The Laker family

hard work and a huge adjustment to all aspects of life. This may mean a parent giving up work for for a while and if that family has more than one child, then siblings may spend some time apart too. By holding a few small events, we hope to give families something special to look forward to.

All these events are in addition to our core service, which is providing nursing care at home and counselling. With your help we can ensure that these additional activities are provided in the future. Please consider donating what you can, so we can continue to create opportunities for families to spend happy, quality time together (See our back page to find out ways to donate).

DONATE

The Snowdrop Touch

Every child and family who joins the 'Snowdrop Pathway', starts a unique journey of care. The relationship they build with their nurses, their counsellor and their support worker, is very special.

But it is not just the nursing team who care about these families – there are our volunteers supporting us at events, the child who saves his pocket money to donate, the customer who buys our merchandise, the schools who picks us as their charity of choice, the community groups who set themselves fundraising challenges and even the raffle ticket buyers who contribute to our fundraising efforts. It is remarkable to see how people from all walks of life are touched by Snowdrop since it was founded in 1993 and are inspired to contribute in so many meaningful ways.

You do not need to know a Snowdrop family personally to make a difference. Just by talking or reading about the charity can help us build our incredible and generous community who are always ready to help local families when



they need it most. Snowdrop families will always have a special link with the Care at Home Team and the Trust. The kindness they receive from the community is forever in their hearts. Please help us to continue to be there making the difference.

Wear your Snowdrop with pride, giving hope and support to the Snowdrop families.

SAVE THE DATE

NOV
24/25

Grittenham
Barn
Tillington

Christmas
Market
10am til 4pm



2024
MAY
12

Annual Walk
at Arundel Castle Estate Park

Walk 1 or 5 miles
from 1pm til 3pm.
Stalls and music

Full details of all our events are on
our website
www.thesussexsnowdroptrust.com

From day one, volunteers in various roles, have been the backbone of the charity.

Snowdrop Family Volunteers were recruited by our first Volunteer Co-ordinator, Ann Saltwell. These wonderful people came from all walks of life and were placed with families to help them in so many different ways. Swimming instructors taught children to swim, giving them confidence and a time for fun! Retired teachers helped children who had lost so much school time because they were in hospital or at home receiving treatment. Volunteer drivers used their own cars to take children and their families to hospitals across the country, as many children attended clinics at Great Ormond Street, London hospitals and Southampton. When Ann retired, Jenny Bush took over training and supporting our loyal team. We were so fortunate to have this band of family volunteers who loved their role within Snowdrop and it was with a heavy heart that the service had to close down due to new rules and regulations brought in by the NHS.

Snowdrop event volunteers have been invaluable ever since we founded the charity. They have stood outside shops with collecting buckets, helped with car

unsung
The Queen's
Voluntary S



and present

evantine, Chairman and Co-Founder

parking at our annual Walk, made cakes, served cakes!, manned stalls, sold jigsaws, opened their gardens, joined us at the much loved Butlins Snowdrop Children's Christmas Party, and so much more. They have, and still do, make a massive difference to our ability to get out there and raise funds, and we do appreciate every minute they give to help us.

This Summer, current volunteers were invited for a fabulous afternoon outing with a magical mystery tour! They were transported by a vintage bus from a bus stop in Walberton, to a lunch at the Black Rabbit Pub in Arundel. It was our way of saying thank you to them for their unstinting support. We hope more people will consider 'Getting Onboard with Snowdrop' as a volunteer. We teamed up with Snowdrop Dad and V2 Radio DJ, Gary Booker on the day who raised awareness for the need for volunteers, live on the radio. It was a great day and lovely to see that friendships were made too.

To celebrate 30 years of Snowdrop, we chose Arundel Town Hall as the perfect setting for a memorable Anniversary Dinner, we invited representatives from our supporters, volunteers, Snowdrop parents, present and previous staff, trustees, old friends and new friends and my supportive family!

heroes Award for service 2005



Community Champions

There are some amazing people in our community. People who give up time to put on an event and dream up great ideas of how to raise funds. Not all community groups know someone personally who has needed the help of the Sussex Snowdrop Trust, but they are still determined to give as much as they can as they have empathy for others in need.

When talking to pupils at a school assembly you can almost feel the energy

Portsmouth High School's outgoing Head Girl Team presented us with a staggering cheque of £10,190.79. This was the sum of a year's worth of events that the team organised. The school holds a 'Charity Week' packed with fun activities including a fashion show, quizzes and a fancy-dress parade. The team liaised directly with local businesses and shops and used their business acumen and entrepreneurial skills to improve their fundraising opportunities. The use of social media by the students also helped raise awareness for the charity. Thank you

Going the extra mile for Snowdrop!

James Baker took on an intense challenge on Coronation Day – running 80km non-stop for 12.5 hours! James explains why. "After running a marathon across the South Downs for The Sussex Snowdrop Trust in 2020, I am attempting to one-up myself this year in order to raise even more money for this incredible charity. Therefore, on the 6th of May I will be running 80km, from my front door in Pagham to Brighton and back.

In 2007 my brother was diagnosed with a rare condition called Aplastic Anemia, a condition whereby the body is unable to produce sufficient new blood cells. During this period, he was treated at St Richards, Southampton and Great Ormond Street Hospital, starting with countless blood and platelet transfusions, chemotherapy and finally a bone marrow transplant from his identical brother/ 'walking bag of spare parts'!"

Throughout this period and for the years of post-treatment care to follow, The Sussex Snowdrop Trust were the backbone of support that my brother

of those enthusiastic to take action and have some fun raising vital funds. 130 students and 9 members of staff from the Regis School in Bognor Regis took on a 15.2 mile challenge called the 'Walk for Change' – walking from Worthing to Bognor Pier. The Trust was one of three charities supported and received an amazing £1360.05! Kevin Robbins, one of the school's counsellors commented, "The students arrived at Bognor Pier after 7 hours of walking to a hero's welcome of parents and well – wishers. This was an excellent opportunity for

to this incredible group of girls for all their hard work and for inspiring the whole school to back their fundraising initiatives in their last year of school.



and our family received. Their relentless care and thoughtfulness, in an incredibly dark time for our family, was something that will always serve as a poignant reminder the impact local charities and genuine kindness can have on people's lives.

Taxis to and from hospitals, a laptop for my brother so he could speak to family and watch films in between treatment, nurse visits to the house, iPods to use while we were travelling to and from hospitals, a home tutor to get him back up to speed from missing school and so, so much more - the things they did for us are seemingly expansive when you think back to the time.



our students to develop resilience and recognise the benefit of teamwork. Some great memories were made on the walk and the sense of satisfaction was immense." We thank the Regis School for giving their students the opportunity to support the community in this way.



'For the Love of Football'

The Trust had the pleasure of meeting a young football team called the Sussex Rangers, led by Paul Law. These players are on a mission to help others in their community whilst having fun with their game. They got together to do various challenges including a run round Hotham Park and our annual walk at Arundel Castle Estate Park. The Team raised £1000! Thank you!



The Barnham Veterans Team has also been working hard with plenty of matches and raffles. To celebrate their success Di Levantine, Chairman and Co-Founder met with Eric Murray who had spearheaded the year of fundraising and an incredible £1745 cheque was presented. Thank you to everyone who contributed with donations.



Snowdrop - 'Hope' in the language of flowers

The Trust started its 30th year events with a photographic competition named, 'Snowdrops – where you least expect them!' and the photographs that were shortlisted were exhibited at Denmans Gardens, Midpines Café near Fontwell. We were delighted to receive so many entries. The winners were Celia Henderson and Sophie Sitwell. Gwendolyn van Paasschen, owner of the gardens also did a talk about 'The Promise of Snowdrop'. Many of the framed photos were sold in aid of the charity and we have some displayed at our offices. We have created two new

notelet packs featuring the winning photographers – 'Snowdrop Tea' by Sophie Sitwell and 'Finishing Touches' by Celia Henderson. These are available online or call us on 01243 572433.



'Happy and Glorious' at Champs Hill

Back in 2013, Mary Bowerman and her late husband were a little reluctant to become Patrons of The Snowdrop Trust as they were giving up many of their roles within the community, and in their world of music and art. However, they did accept, and we are blessed to have had their support for many years. Mary has enabled us to have four concerts at Champs Hill for Snowdrop, and this year she organised a stunning 'Happy and Glorious' flower arranging demonstration with Matthew Spriggs, and generously provided lunch too.



V.I.P. Visitors

The Sussex Snowdrop Trust was delighted to receive an award in recognition of its work from the outgoing High Sheriff of West Sussex, James Whitmore. This is a huge honour, and we are beyond proud of all the Care at Home Team, our office staff, and volunteers. This is for all of them and to all our supporters and fundraisers who contribute to the Trust.

The certificate reads 'This award was made by The High Sheriff of West Sussex to The Sussex Snowdrop Trust in recognition of great and valuable services in the community. The award also recognises the appreciation of the residents and people of said High Sheriff's County for activity and contribution in enhancing the life of the community.'

We are so grateful to the High Sheriff of West Sussex, James Whitmore who has taken the time to get to know the charity and given this award.

The charity was also graced with a visit from The Lord-Lieutenant of West Sussex, Lady Emma Barnard.

The Lord-Lieutenant is the King's representative who upholds 'the dignity of the Crown by promoting a spirit of co-operation throughout the county, in encouraging voluntary service and charitable work, and taking an active interest in the business, industrial, social and cultural life of West Sussex.'

Lady Emma learnt about the history of the charity with Co-Founder Di Levantine, who has volunteered in her role since the charity was founded in 1993. She also spoke with Phil Portway who has been the Trust's counsellor for 17 years.



Who we are...

Diana Levantine

Chairman & Co-Founder

Valerie Seddon

Vice Chairman & Trustee

Trustees

Caroline Bechelet-Carter

Nick Cockram

Tony Jago

James Tickell

Dr Marco Cavaroli

Patrons

Mary Bowerman

Tommy Boyd

Hugh Dennis

The Rt Hon. the Lord Herbert

of South Downs CBE

Dame Patricia Routledge DBE

Rt Rev. Bishop Richard Moth

(Bishop of Arundel & Brighton)

Rt Rev. Dr Martin Warner (Bishop of Chichester)

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Registered Charity No. 1096622

Limited Company No. 4557686

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Christmas Cheer

Spread some Christmas cheer with our selection of Christmas cards this year- prices range from £3.50 for a pack of 10. The full selection is available on our website; www.thesussexsnowdroptrust.com or pop along to our Walberton office to purchase.



Make a Donation

You can make a donation by:

- ♥ Filling in the donation form below and returning to us by post to the Walberton Office.
- ♥ Visiting our website: www.thesussexsnowdroptrust.com and click on the green heart to donate.
- ♥ Setting up a Standing Order with your bank:
Sort code – 30-91-97
Account number – 02271507
- ♥ Leave The Sussex Snowdrop Trust a legacy in your Will – talk to your solicitor about how to do this.

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Please call the Snowdrop office
on 01243 572433
to make a donation by card.



Text the word SNOWDROP to 70085
followed by the amount you'd like to donate
for example: Snowdrop 10 to donate £10
Snowdrop 20 to donate £20 etc

N.B. Your usual standard rate message charge will apply



Donation Form

Date

I/We would like to make a donation and enclose £

Title

First Name

Surname

Address

Postcode

☐ **PLEASE TICK IF ELIGIBLE.** Please treat this donation as Gift Aid. I confirm I have paid or will pay an amount of Income Tax and/or Capital Gains Tax for each tax year (6 April to 5 April) that is at least equal to the amount of tax that all the charities or Community Amateur Sports Clubs (CASCs) that I donate to will reclaim on my Gifts for that tax year. I understand that other taxes such as VAT and Council Tax do not qualify. I understand the charity will reclaim 25p of tax on every £1 that I give on or after 6 April 2008.

Please make your cheque payable to The Sussex Snowdrop Trust and send your donations to:
The Sussex Snowdrop Trust, Unit 3 The William Booker Yard, Walberton, West Sussex BN18 0PF.

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