Winter 2021
ISSUE No. 4
Registered Charity No 294354

South West Wales Branch

Newsletter

ROUND UP

Welcome to the Winter Edition of our Branch Newsletter…………

Whilst it has been a ‘journey’ navigating through the COVID pandemic and restrictions, the branch has been able to continue fundraising and raising awareness, albeit virtually. Our primary aim continues to provide the support and care to the people who need it, and thanks to our many volunteers, AVs and carers we have managed to persevere.

We are edging close to face-to-face meetings again for the monthly committee get-togethers but ‘virtually’ we have still managed to discuss, plan and share ideas.

There are plenty of brilliant fundraisers out there doing fantastic things to continue raising crucial funds and awareness, not only for our SWW Branch but the wider MND community, and some of them are featured in this edition of our newsletter.

Once such remarkable man and his army of supporters is Bob Gledhill. His MotorOn campaign has done some truly epic challenges. Read all about this on pages 3 to 5.

We would also like to congratulate Jon and Kelly (both committee members) on finally tying the knot last month (after copious amounts of rescheduling) – we wish you both all the very best in married life.

As always, please do get in-touch if you would like to see your news featured in the next issue.

Adapt Now – Welsh Homes for MND

Adapt Now
Welsh Homes for MND

Addasu Nawr
Cartrefi Cymru ar gyfer MND

Due to the differing political landscapes between England and Wales, the decision was made to stop the roll out of the national Act 2 Adapt Campaign in Wales.

Wales focus would become the Welsh Homes for MND campaign to provide clarity for those living in Wales. The campaign is supported by Peter Fox MS.

The main aims for Welsh Homes for MND are:

- Ensuring local authorities have a transparent, fast-track, non-means tested process for housing adaptations
- To remove means testing for adaptation applications

One planned action is to email all Welsh councils asking them to adopt the fast track process for those living with MND.

We are glad to say that Swansea council has recently adopted the MND Charter and Neath Port Talbot council is looking likely to follow suit.

Last month there was a virtual event held, with the Senedd, that gave those living with MND and their families the opportunity to share their experience of the housing adaptation process. This was an open virtual event that allowed our campaign a voice within the Senedd.

The working group is aiming to meet again on 29th November to discuss progress and plan targets for 2022."

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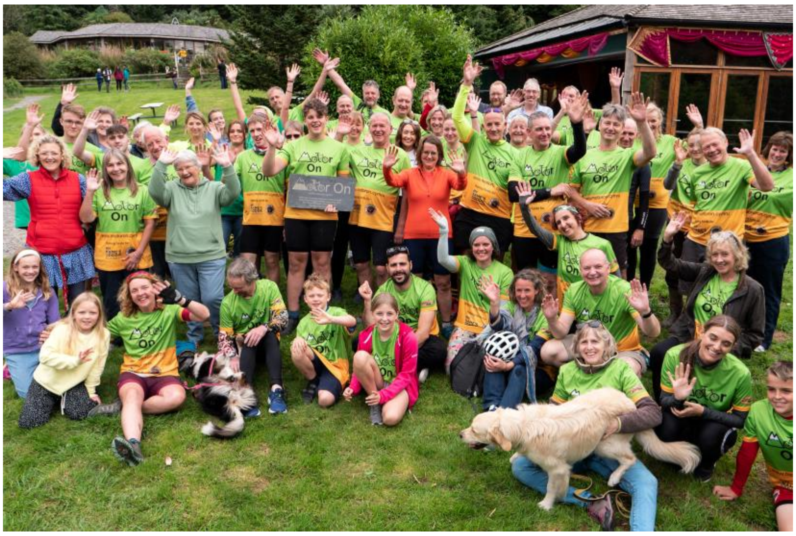
Rollercoaster Summer as MotorOn Cymru Raises over £65,000

It's been a roller coaster summer for Bob Gledhill and his family, who live in Rhyd-ar-gaeau, near Carmarthen. In July, the family led the 'Motoron Cymru Challenge', climbing the Welsh Three Peaks and cycling between each one, raising £65,000 for the 'My Name'5 Doddie Foundation' and the Skanda Vale Hospice. In August, the Motoron team cycled from Snowdon to Edinburgh to present a cheque to the foundation and in early September, they cycled from Pen y Fan to Carmarthenshire, to deliver funds to Skanda Vale.



Staying positive

The Motoron story starts with Bob Gledhill, from Carmarthenshire, who was diagnosed with MND in early October 2020. While MND patients in other parts of Wales are automatically referred to specialist units in England, this isn't the case in West Wales, and following diagnosis, Bob experienced delays in accessing the local neurology service.

Bob, an outdoor enthusiast originally from Huddersfield, explains: "Following the trauma of diagnosis, I felt abandoned by local services – what I really needed was a prompt referral to a specialist MND centre, and this didn't happen for several weeks. It was also difficult to get hold of detailed information about the disease and how best to manage it."

Despite the terrible diagnosis, Bob, his wife, Lowri Davies and their son, Will, were determined to live each day to the full. Staying positive and active, contributing to MND research and making a difference for MND patients down the line is hugely important to Bob – and so the family settled on an extreme sports challenge, to raise funds to support both MND research and the work of the Skanda Vale Hospice.

The Challenge

Over the weekend of 2-4 July, around 200 family, friends and supporters joined Bob to undertake the 'Motoron Cymru Challenge', which involved climbing Wales' three highest peaks, Yr Wyddfa, Cader Idris and Pen y Fan, cycling between each one.

On Friday, 2 July, the team scaled Snowdon. They had an early start the following day, setting off at 6.30am to cycle south to Dolgellau, before climbing Cader Idris. Sunday, 4 July was the toughest day – a grueling cycle ride through mid-Wales, before climbing Pen y Fan, the highest mountain in southern Britain. All in all, the team cycled almost 150 miles and climbed around 2,062m.

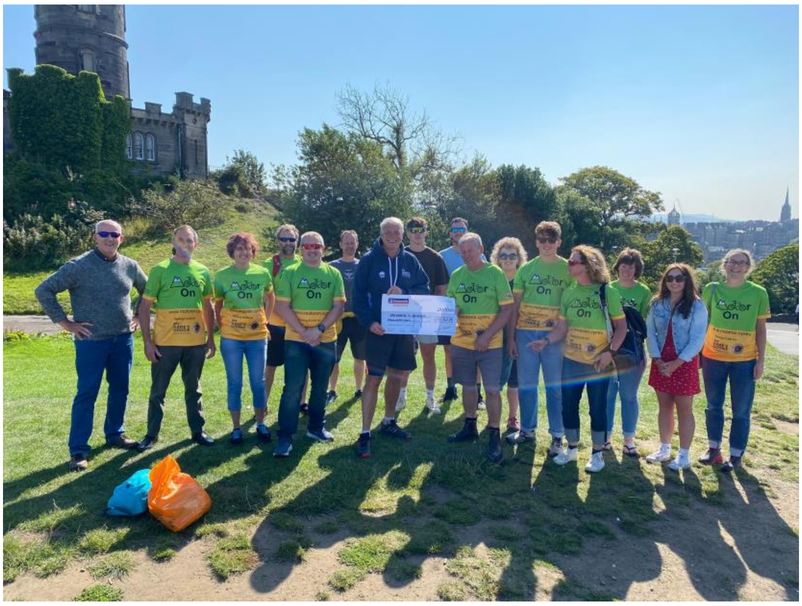
"Planning and training for the Motoron Cymru Challenge was a brilliant way to stay active and positive in the face of the MND diagnosis," says Bob. "We had a great weekend, with so many friends and family taking part. The weather was mostly kind and we had lots of support along the way."

The challenge raised over £65,000 – smashing the original target of £10,000 – but it didn't stop there. Lowri Davies adds: "It was such a fantastic experience, we didn't want it to end – and so we decided on a second challenge, to cycle from Yr Wyddfa to Edinburgh, to present the funds in person to the 'My Name'5 Doddie Foundation'."

'My Name'5 Doddie Foundation'

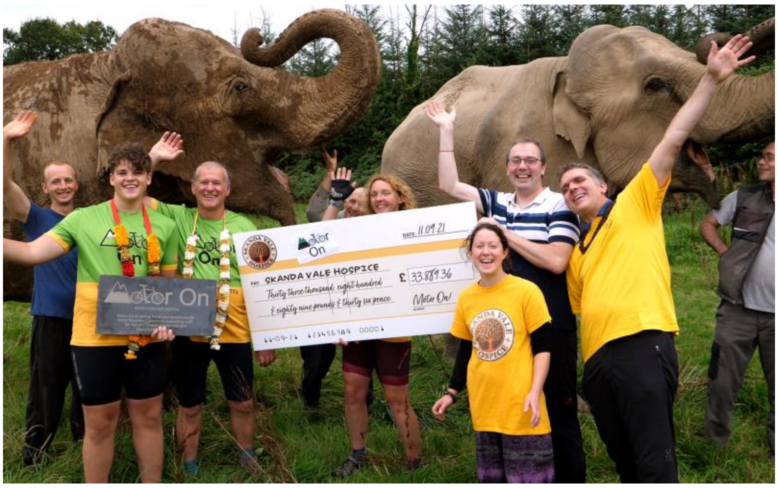
Set up by former international rugby player Doddie Weir OBE, who earned 61 caps for Scotland and who revealed he was suffering from MND in 2017, the aim of the foundation is a world free of MND.

Led by Bob, a squad of Motoron supporters cycled 330 miles over five days – without one puncture! – to present a cheque for £31,500 to the foundation. They were met on Calton Hill in Edinburgh by former Scottish rugby star, Scott Hastings, who accepted the cheque on behalf of the foundation.



Skanda Vale

The Gledhill family has a long-standing association with Skanda Vale, as Bob's wife, vet Lowri, cares for the community's many animals, which include two Asian elephants, Lakshmi and Valli. Skanda Vale also runs an independent hospice, founded by monks and nuns from the community's multi-faith monastery. The hospice team has very few paid staff – the team is made up, almost entirely, of highly-skilled volunteers.



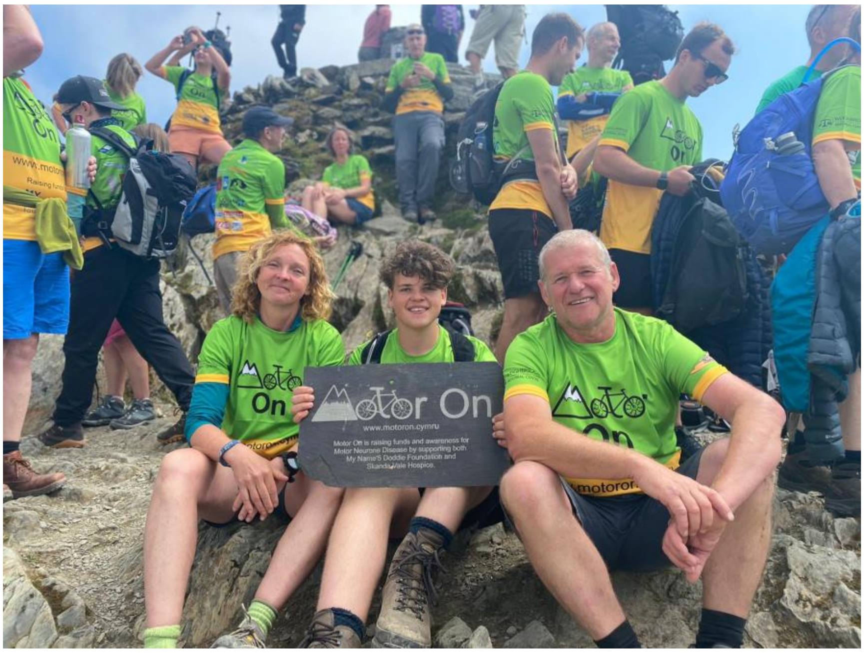
Crowds of well wishers, along with elephants Lakshmi and Valli, welcomed the Motoron team in early September, after they had cycled around 60 miles from Pen y Fan to present a cheque for £33,889.36 to the hospice.

Bob explains, "There's always a warm welcome at Skanda Vale, but it was amazing to cycle into the community that day – it was a day to remember, full of friendship and an opportunity to celebrate a fantastic achievement."

Diolch!

Bob, Lowri and Will are grateful to the many sponsors who supported the challenge along with all the friends, relatives, colleagues and volunteers who got involved in Motoron Cymru.

Lowri adds: "We're facing a big challenge as a family, but to have so much support means the world - we're not walking this path alone, and that makes all the difference."



What next for Motoron?

Bob, Lowri and Will are already thinking about the next challenge, with talk of a sponsored cycle ride in the South of France in 2022, to include one of the key climbs of the Tour de France.

The family is also thrilled to hear that SMART trials are due to start soon in Wales and are hopeful Bob will be able to take part.

"To be able to contribute to MND research and make a difference for others, in the future is hugely important to me," adds Bob. "Being part of a larger community trying to find a treatment for MND also helps me stay positive."

The family will continue to raise awareness of MND along with the need for improved access to specialist care. Delivering more wide-ranging support for families of MND sufferers is also a priority.

To donate to [Motoron Cymru]() click here. More information is available [here]().

Local Business Donations

Bridgend
Mobility
Centre
tel 01656 723272
web www.bridgendmobilitycentre.com

We would like to take the opportunity to thank Bridgend Mobility Centre for their generous support over the last year.

Bridgend Mobility Centre work with a number of charities to provide discounts on their products.

They currently donate £25 from every stairlift sale as a result of sales channelled through our branch and pay a monthly donation to us.

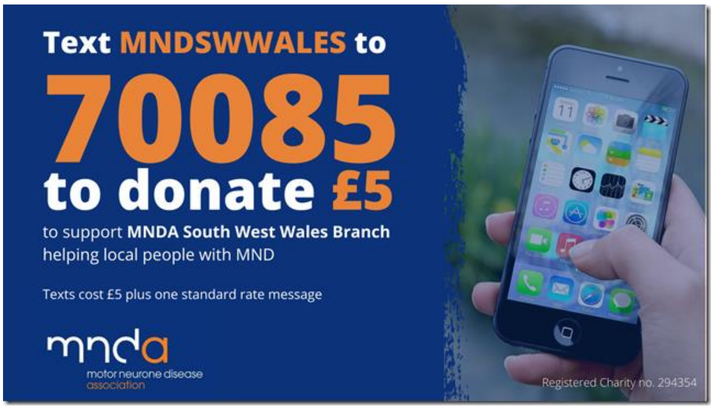
Director Kristian Tobin quotes "*The MNDA are a charity close to my heart and I hope we can continue supporting them and raising more vital funds in the future*"

Gifts

By Design
Gifts for you and your home

Lesley & Kirsten have pledged to donate 15 % of all sales from their website http://www.bydesigngifts.net Please use the voucher code **MNDA**

Text to Donate



Text MNDSWWALES to
70085
to donate £5
to support **MNDA South West Wales Branch** helping local people with MND
Texts cost £5 plus one standard rate message
mnda motor neurone disease association
Registered Charity no. 294354

Our Branch now has a 'Text to Donate' facility. This is the code and sentence that needs to be used. The donor can change the amount donated by simply adding the gift amount as required e.g. MNDSWWALES 10 for £10

MNDSWWALES to 70085 to donate £5
Texts cost £5 plus one standard rate message.

motor neurone disease association
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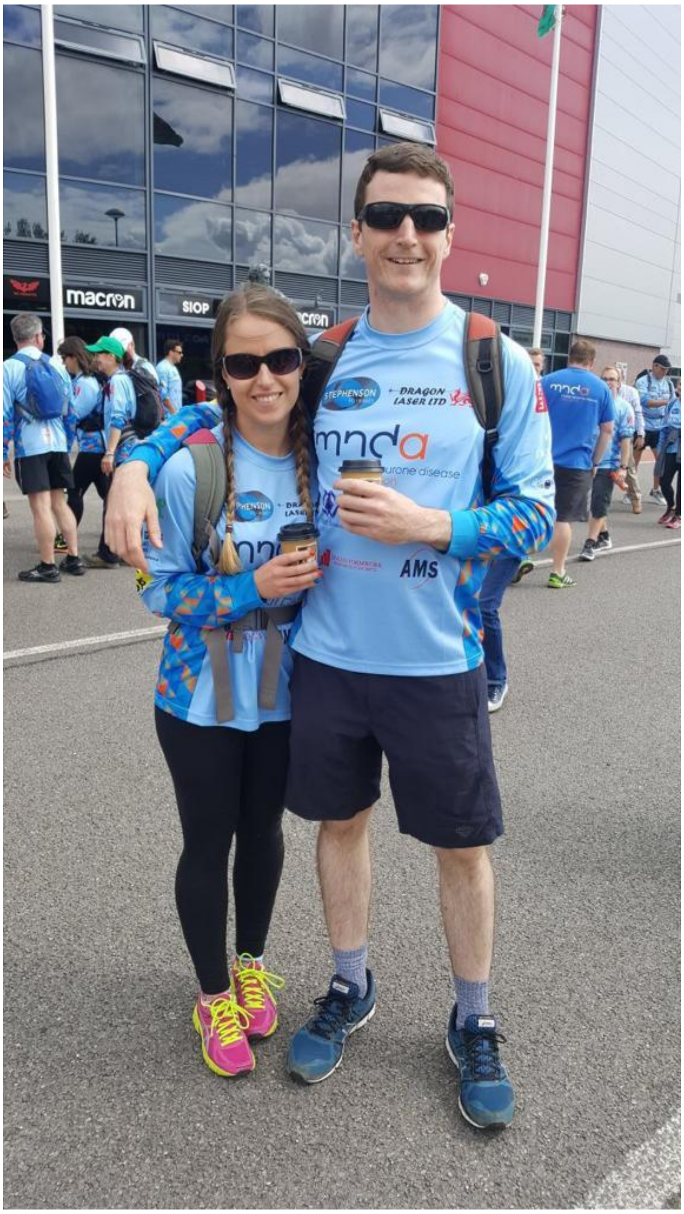
Meet our Members - Kelly Price



I first heard about Motor Neurone Disease when I met my husband Jon (also pictured), who sadly lost his mum to the disease. I was struck by the devastating impact of this condition and the challenges individuals face, in part due to the lack of awareness.

Before I knew it, I was signed up to the Climb4MND challenge and we took up our places on the committee, with a hope of supporting the much needed fundraising and importantly raise as much awareness of MND as possible.

Since then I have joined Justin and Jon on other fundraising challenges such as Kayak4MND and Stadium2stadium4MND, as well as organising fundraising events including a 24hour row for MND and 12 hours of CrossFit workouts.

I feel lucky to be part of such a great team and hope to support the MND community in any way I can. Within our role, Jon and I are campaign contacts, working closely with MNDA Wales to raise concerns and lobby for changes needed to support those suffering with MND.

We also run the social media pages on Facebook, Twitter and Instagram.

We always love to hear from you and share your stories, so please don't hesitate to get in touch!

We never lose hope. We strive to find a cure for MND and to support everyone affected by this devastating disease.

MND Care Centres and Networks

Since 1990, the MND Association has developed a number of MND Care Centres and Networks across the UK including the South Wales Care Network based out of Morriston Hospital, Swansea.

They improve the support and co-ordination of services for people living with MND. They also promote effective, integrated working between health, social, research and voluntary sectors.

They do not replace an individual's existing care team, but work in partnership with them to promote and develop effective service delivery.

If you are in any doubt about where you can receive care and support, your MND Connect will be able to help you.

Resources for Carers

There is a range of updated resources for carers on our website here:
https://www.mndassociation.org/support-and-information/for-carers/support-for-carers/

This includes carer **wellbeing audio and video resources** led by two experienced practitioners (scroll down towards the bottom) – please do share these resources with carers you are in touch with, as we would really value feedback on these

There is a facility to add **support groups or events for carers** here:
https://www.mndassociation.org/support-and-information/local-support/carers-groups-and-events/
Please can you all use this to add any event or group which can be accessed by carers in your area and encourage branches & groups to do the same

There is a section specifically for **bereaved carers** here: https://www.mndassociation.org/support-and-information/for-carers/bereavement-support/ and a **new forum thread: *living with bereavement*** alongside the existing ***caring for someone with MND*** thread here:
https://forum.mndassociation.org/forum
This has all been developed by the bereavement/end of life working group – please do share these resources as required.

FINANCIAL STUFF

Income and Expenditure to September 30th 2021			
Income		**Expenditure**	
	Year to Date		**Year to Date**
General Donations	5401.36	Financial Support	1817.90
In Memorium Donations	2310.00	Equipment	58.49
Tribute Funds		AV expenses	137.67
Corporate Donations		Carer Support	1970.00
Grants		Care Spend to DNH	7014.45
Other		Other	2679.96
Total Donations Received	***7,711.36***		
Fundraising – Branch	5,260.34		
Fundraising – Others	3,132.65	***Total Care Expenditure***	***13678.47***
Total Fundraising Income	***8,392.99***	Meeting Costs	
Bank Interest	7.35	Printing, Postage & Stationery	
Gift Aid	853.91	IT Costs	
Other	661.00	Purchases via MND(Sales) Ltd.	88.00
Total Other Income	***1522.26***	Other	1.26
Total Income	**19096.94**	***Total Branch Admin Costs***	***89.26***
Net Income	**4492.22**	**Total Expenditure**	**14604.42**

Allocation of funds this year have included:-
16 Heating grants - £150 each
3 support Grants – 1 ceiling track hoist -£550, 1 towards a wet-room - £1000, 1 for a riser recliner chair -£500
2 Carer's Grants – various items to support Carers

Coffee Mornings

You are invited to our forthcoming coffee mornings. These events are an opportunity for people living with MND and their carers to drop in, meet others and have a relaxing cup of coffee/tea in a comfortable setting. We hope to provide a comfortable informal occasion where ideas can be exchanged, new friendships forged, or old acquaintances renewed.

The venue is the Sir Galahad Room, Morgan's Hotel, Somerset Place, Swansea SA1 1RR; between 11:00 and 13:00. Parking is available opposite the hotel.

Future dates:

Friday 26th November 2021
Friday 17th December 2021

We would be grateful if you could let us know if you will be attending – we need to know numbers for Covid safety purposes.

For further information, help with transport or for details of future events please phone Maimie Davis Tel: 01554 777993; maimiedavis@maimiedavis.plus.com or Frances Rees Tel: 01792 203841

We look forward to seeing you.

Whilst we are starting up face-to-face coffee mornings again, we are aiming to also continue with South Wales wide virtual cuppa and chats so that people have the option of joining either or both. These are in the process of being set up and information will be coming out in due course. If you are interested in attending either of these and aren't on the mailing lists for them please contactMaimie Davis on 01554 777993 or maimiedavis@maimiedavis.plus.com, or Carol Smith on 01604 800615 or carol.smith@mndassociation.org letting them know which you would like to join and your details will then be added to the lists so you receive invitations.

Xmas Competition

Our Christmas card competition is now open and will run until midnight on Tuesday 30 November. Children and young people aged 16 and under are encouraged to design a bright and colourful Christmas card design which will then be printed and sold via our online shop in Autumn 2022. Last year's winners will be available to buy from our online shop when it relaunches in early November.

We would love it if you could help us promote this far and wide with educational partners, People living with MND and People affected by MND. We will be sharing posts across our social channels today to announce it has opened so please do share them and retweet.

For more info, see our webpage: www.mndassociation.org/christmascard

GET IN TOUCH

As always, please do contact the committee if you have any news or events you would like to see featured in the newsletter and promoted through our social media channels.

https://www.facebook.com/MotorNeuroneDiseaseAssociationSouthWestWales/

Twitter: - *@SWWalesMNDA*

Do not forget, this newsletter is also available by email by contacting us or on our website at www.mnda-southwestwales.org.

Useful Contacts

MND Connect offers support, information and advice to people living with MND, health and social care professionals, staff and volunteers.

mndconnect
0808 8026262
mndconnect@mndassociation.org

The South Wales MND Care Network is a network of healthcare professionals providing specialist care and support across South Wales. The South West Wales office covers our area and can be reached on: 01792 703705 or by email abm.southwestwalesmnd@wales.nhs.uk

Branch Contacts

Chairperson	Janet Fisher	(07484 822120)	jan@mnda-southwestwales.org.uk
Branch Contact & Treasurer	Maimie Davis	(01554 777993)	treasurer@mnda-southwestwales.org.uk
Committee members	Lesley Frost Kelly Lewis Mike Cottle		
Newsletter / Website	Justin H-Davies		jdnspis@hotmail.com
Social Media	Jon Price / Kelly Price		Jon.price86@live.com

This newsletter was published by the South West Wales branch of the MND Association. If you no longer wish to receive information from us, please contact jdnspis@hotmail.com or a member of the committee listed.

We never lose hope. We strive to find a cure for MND and to support everyone affected by this devastating disease.