The Independence

Spring/Summer 2026

The **Thalidomide Society** Newsletter

See inside

Hello and welcome to our newsletter!

Direct payments talk with Neil Spooner

I hope you are all enjoying the beautiful weather and the longer evenings the summer brings us.

I would like to thank everyone who attended this year's Annual General Meeting/ Conference. Despite missing some familiar faces, it once again was a highly successful event, with lots of positive feedback. The day had a packed agenda and proved productive for us all. A special thank-you goes to our speaker, Neil Spooner, who is an expert in direct payments and was more than willing to answer the many questions from the audience. I would also like to thank Claire and Sally from the Trust, who reminded attendees of the support the Trust can give.

Julie and I gave a short introduction to our newest project, *Living with Thalidomide*, which we are hoping to launch shortly. The project will provide volunteers the opportunity to go into their community and tell their story. More information is on page 10 of this newsletter.

The workshop groups, again this year, concentrated on the *Maintaining our Dignity and Independence* project and confirmed our understanding of beneficiary needs for future planning. It certainly proved we are moving to a place of understanding our needs better. Last but certainly not least, a big thank-you goes to Roz, Julie, and Heather for their superb organisation of the weekend. The planning ensured the event ran smoothly and was a pleasure for all involved. Do you know that next year will be our 65th birthday? So look out for the dates of the Annual General Meeting/Conference and what we are planning. I hope you continue to enjoy this marvellous summer, and we look forward to keeping you updated with more exciting news and developments soon.

Mandy De La Mare – Chair

Trustees – 2026

- Chair – Mandy de la Mare
- Vice Chair – Ed Freeman
- Line Manager – Geraldine Freeman
- Temp Treasurer – Darren Mansell
- Sue Gooding
- David Tickell
- Eddie Freeman
- Margaret Hogg
- Roz Hepple
- Elaine Hulme

Dates for your diary

Personal Support *Best Practice when employing a personal assistant.* Thursday 9th July.
Thalidomide Memorial Day
Tuesday 30th June.

The Thalidomide Memorial

This year will mark the 10th Anniversary of the dedication of the Thalidomide Memorial, and as always we will mark Thalidomide Memorial Day on the 30th June, through the Memorial social media platforms and through the Thalidomide Memorial website – http://www.thalidomidememorial.com

The annual Roll Call will include the names of members of our Thalidomide Family (and of course, their family members) who have been made known to us, who have left us over the period from 1st July 2025 to 30th June 2026. But if you wish to have someone specifically included in this year's Memoriam, please could you send an email by the 22nd June to rosie@rms-consultancy.co.uk.

The Oral History Project call out for children...

The *Oral History Project* interviewers are moving towards the end of this amazing project, and we would very much like to invite your children to come forward to be interviewed about their personal experience of being a child of a Thalidomider. All interviews will take place in the strictest confidence and will be part of the larger *Oral History Project* that will be stored at the British Library.

We are kindly asking members to please approach your child or children and ask them to get involved. Your child will be able to decide how their interview is to be accessed by researchers and the general public. We all know how important this project is for our future legacy, and thank you for your continued commitment.

If you would like further information, please email Craig Millward at: pinkpiglets2000@yahoo.co.uk or Julie Dixon at: julie@thalidomidesociety.org.

This final part of the project is funded solely by the Thalidomide Society.

Operations update for the Thalidomide Society

We would like to let you know that there is a slight change to the operations team in that Heather and Julie will be job sharing the position of Operations Manager of the Society.

Julie will be working 10 hours on Tuesdays and Wednesdays.

Heather will be working on Mondays, Tuesdays and Thursdays.

Julie and Heather

Mikey Argy

Darren Mansell, Treasurer

Eddie Freeman Vice chair, Mandy De La Mare Chair, and Julie Dixon Operations Manager

The Thalidomide Society Annual General Meeting and Conference 2026

The Thalidomide Society's 2026 Annual General Meeting (AGM) brought members together for a day of reflection, discussion, and planning.

A central part of the meeting included the formal approval of the previous year's minutes, followed by the Chair's report, which highlighted achievements such as the *Oral History Project*, enhanced personal support initiatives, and the relaunch of *The Independent* newsletter. The Treasurer presented the financial overview, reporting an income of £32,069 against expenditure of £76,539, with total reserves standing at £435,665.

Claire Blythe and Geraldine Freeman

Sally Sheehy

At the workshop

Trustees Mandy, Geraldine, and Darren were re-elected, and Elaine was formally elected to the board after being co-opted in April 2025.

Following on from the Annual General Meeting, a key highlight of the Conference was a presentation by independent living advisor Neil Spooner on direct payments and the employment of personal assistants (PAs). His session offered practical insights into the assessment process, the responsibilities of being an employer, and the flexibility that direct payments can provide. Members shared their own experiences, discussing both the benefits, such as increased independence, and challenges, including recruitment, administrative burdens, and navigating local authority processes.

Sally and Claire from the Thalidomide Trust provided an overview of the wide range of support services available to beneficiaries. This included health and well-being support, guidance for social care assessments, and resources such as personal assistant recruitment packs and support planning tools. They also highlighted funding opportunities through the Grunenthal Foundation, including support for personal assistance.

This was followed by an inspiring introduction to a new community outreach initiative and volunteering opportunity, *Living with Thalidomide*. This project aims to empower members to share their personal stories within local communities. Mandy shared her positive experience of delivering talks, highlighting the strong and meaningful responses she has received from audiences.

Reflecting on her growing involvement, Mandy noted that she has another talk scheduled next week and is continuing to receive bookings through to the end of the year. She encouraged others to consider getting involved, describing it as a truly worthwhile experience and emphasising how audiences are often amazed by the full and accomplished lives lived by members of the community.

The volunteering opportunity will include training and ongoing support for those interested in taking part. For more information, please email info@Thalidomidesociety.org.

As a mark of respect, the morning finished with Simone Illger reading her poem and a minute's silence for those friends lost in the past year.

The afternoon session provided an opportunity to support the project, *Personal Support, Maintaining our Dignity and Independence*, for important discussions around daily living challenges and evolving care needs while maintaining independence. Members exchanged valuable peer insights on topics such as managing direct payments, building relationships with carers, and adapting to changing health conditions.

The 2026 AGM/Conference demonstrated the strength of the Thalidomide community, highlighting both shared challenges and collective progress. With continued collaboration, advocacy, and support, the Society remains committed to empowering its members and shaping a more inclusive future.

Direct Payments

They never asked me

Kindly read by Simone at this year's Annual General Meeting. Thank you for sharing, Simone. Poetry by Simone with assistance of Chat Generative Pre-trained Transformer (ChatGPT).

They never asked me, they never warned my mum,
a tiny little pill in her hand
"Thalidomide, harmless,"
they'd hum.
Helps with sickness and helps you sleep, nothing more.
But beneath that calm, the storm was waiting at the door.

I was born amid headlines, whispers, and stares,
People counting what was missing instead of noticing what was there.
Short arms, three fingers, no thumbs on each side,
They measured my body, but never measured my pride.

Doctors listed limits as if they knew who I'd be,
while my mum saw a spark only she could see.
Dad said she'll never do this, writing fears like a list,
Mum said she's got a finger for a wedding ring, don't dismiss.

So we learned, not the way others learn but in our own way.
Turned what they called a disability into strength every day.
Jobs, marriages, children, yeah, we fought every fight,
every small victory felt like reclaiming our right.

They called us all victims, but we refuse that name;
we are survivors, challengers, you will remember our flame.
They saw what we didn't have and called it a flaw,
every "can't" became a win that left them wide-eyed in awe.

We don't want pity, we're not here for your sorrow.
We want respect, hard-earned, not borrowed.
They tried to define our future with clinical doubt,
but how we've lived our lives drowns that noise out.

We were scattered across countries, oceans apart, different languages spoken, but the same fire in our heart.
Same story, same struggle, same silent fight,
born into battles we never chose, yet we rose to the light.

From Canada to Germany, Japan to the UK,
we found one another and built something they cant take away.
We don't share blood, we share courage, shared scars, a global constellation survivors shaped like stars.

We're not just individuals, we're a worldwide family, linked by resilience, bonded through tragedy.
They measured our limbs, but never knew our worth, we're proof of strength on every corner of earth.
We're a worldwide family bonded in the rarest way, but time keeps moving, and it takes our own away.
We've shared laughs, shared battles, shared every scar, now we're lighting candles for the ones who've gone too far.

We feel every loss – it echoes in our chest, because each one leaving takes a piece of all the rest.
We were warriors from birth; we were never meant to hide,
but even warriors grow tired from the mountains we've climbed.

Names turn into memories, faces into air,
and we honour them in stories, in the courage that we share.
We hold on to each other, this family, worldwide, because every goodbye reminds us how precious it is to still be alive.

Simone Illger

In Memory

We remember those from our community who have passed away this year.

We are not always able to acknowledge everyone if their family doesn't feel able to allow us to do so.

- Lesley Moseley
- Dorothy Taylor
- Sally Anderson
- Michelle Allnut
- Jayne Peacre
- Gerard Cleary
- Jackie Hellawell
- Sukeshi Thakkar

Tom and Rosaleen Moraiarty-Simmonds


Tom and The Duchess of Edinburgh

Tom reaches top of organisation

Alton artist Tom Yendell has been elected president of the Association of Mouth and Foot Painting Artists (MFPA).

After 40 years as a member Tom has reached the top of an organisation which works to help 800 artists around the world who paint with their mouths and feet achieve commercial success.

He was elected at the association's Delegates Convention, during which elected senior artists voted on behalf of all the members to choose their president and members of the Artists International Management Board.

The association is 70 years old this year and celebrated with an exhibition at Lindley Hall in London to which Tom contributed.

Tom was born without arms and hands due to his mother being prescribed Thalidomide during pregnancy.

He grew up using his mouth, feet and chin to do everyday tasks, teaching himself to draw and paint with his feet and later his mouth.

Tom went to Treloar's before earning a bachelor of arts degree in expressive arts at Brighton University. He joined the association as a student artist in 1986, was elected to the Artists International Management Board in 2013, and last year was made an Officer of the Order of the British Empire (OBE) for outstanding contribution to young people with disabilities.

He said "I knew about the Mouth and Foot Painting Artists from a very early age. Little did I know however, in 1989, when I stood watching the then minister for the disabled open an MFPA international exhibition at the Royal Festival Hall, that I would rise up the ladder in the association to become its president.

"Becoming president of the International Association of Mouth and Foot Painting Artists is the highlight of my 40th year being involved with such an amazing organisation. I am so proud. I get the chance to give something back to our fantastic company, as it provided so much for me both artistically and financially."

The Thalidomide Society Lottery

Support our lottery and help fund the Thalidomide Society's vital projects – including our Oral History work, preserving members' stories for future generations.

- Play for the chance to win up to £25,000 with 1 in 63 odds.
- At least 50% of every £1 goes straight to our charity.
- Anyone can join – members, families, friends, supporters, organisations.
- You have to be in it to win it.
- Join here: www.unitylottery.co.uk

- T&Cs: 16+, GB residents.
- Rules & odds: https://www.unitylottery.co.uk/rules/
- How winners are selected: https://www.unitylottery.co.uk/prizes/

Promoter: Marie Pearse (Member & Promoter)

UNITY

Play now... www.unitylottery.co.uk/causes/the-thalidomide-society/

Become a volunteer "Living with Thalidomide"

Living with Thalidomide is a new volunteering project to help preserve your legacy in your local community. Join a meaningful initiative with full training and ongoing support provided. A platform for growing awareness. Remember, Educate & Advocate.

The Society will support you to:

- Create your story
- Find local groups to speak to
- Borrow prop's

To find out more or register your interest email info@thalidomidesociety.org

"I really do hope that some of you may consider taking this on, as it is a worthwhile cause, and people are amazed by the full lives we have all lived."

Mandy De La Mare – Chair

LIVING WITH THALIDOMIDE

The Personal Support Project so far

The Personal Support Project has been all about helping Thalidomiders keep their dignity and independence by better understanding the support options available to them.

So far, we've spent time listening to the community, gathering feedback, and learning from people's real life experiences to make sure the project reflects what matters.

We've pulled together a range of case studies to show what good personal support can look like in practice. Alongside this, we've hosted Zoom sessions for the Thalidomide community and their support networks, giving people the chance to hear directly from professionals with experience in funding advice and personal support.

Three main Zoom meetings have taken place so far: one focused on how to fund your support, and another looked at what support is available. These sessions were designed to be practical and easy to access. Recordings can be requested by contacting the Thalidomide Society, and we're planning to make them available on the Society's YouTube channel in the future.

We've also spoken with a support agency manager to talk through the key things to think about when employing a Personal Assistant privately, as well as what people can expect when working with a care agency. This has helped highlight some of the important questions and decisions people may face.

As the project moves towards its final stages, we're working on supportive help sheets to make it easier for Thalidomiders and their families to understand care needs, Direct Payments, employing personal assitants, and how to maintain dignity through good practice and shared learning. Feedback shared at last year's Annual General Meeting has played an important role in shaping this work, and those views have been listened to and taken on board.

Future Independence Matters 2026 – diary dates

The Thalidomide Trust's *Future Independence Matters* is a virtual health and wellbeing themed event held across June. The remaining diary dates are below. To find out more go to https://thalidomidetrust.org/news/events/future-independence-matters/

Thursday 25 June		Tuesday 7 July
Realities of a social care assessment and organising care		Future Independence Matters
A practical walk through of Local Authority (LA) processes and financial assessments	Benefits of a Personal Assistant (PA) and how to organise support	Virtual Coffee Gathering
10:15 – 11:30	13:30 – 15:00	14:00 – 15:00

Do you have a story, tip, or anything else of interest to share with other members? We are always on the lookout for features from members for the newsletter; please do get in touch with Heather by email at heather@thalidomidesociety.org.

The Thalidomide Society, The Old Doctors House, 74 Grange Road, Dudley, West Midlands, DY1 2AW.

www.thalidomidesociety.org
info@thalidomidesociety.org

The Thalidomide Society is a charitable incorporated organisation. Registered Charity in England and Wales (No. 231708).

Julie Dixon, Operations Manager
julie@thalidomidesociety.org
07802 604 205

Heather Trueman, Operations Manager
heather@thalidomidesociety.org
07933 121 300

Thalidomide Society
Est. 1962