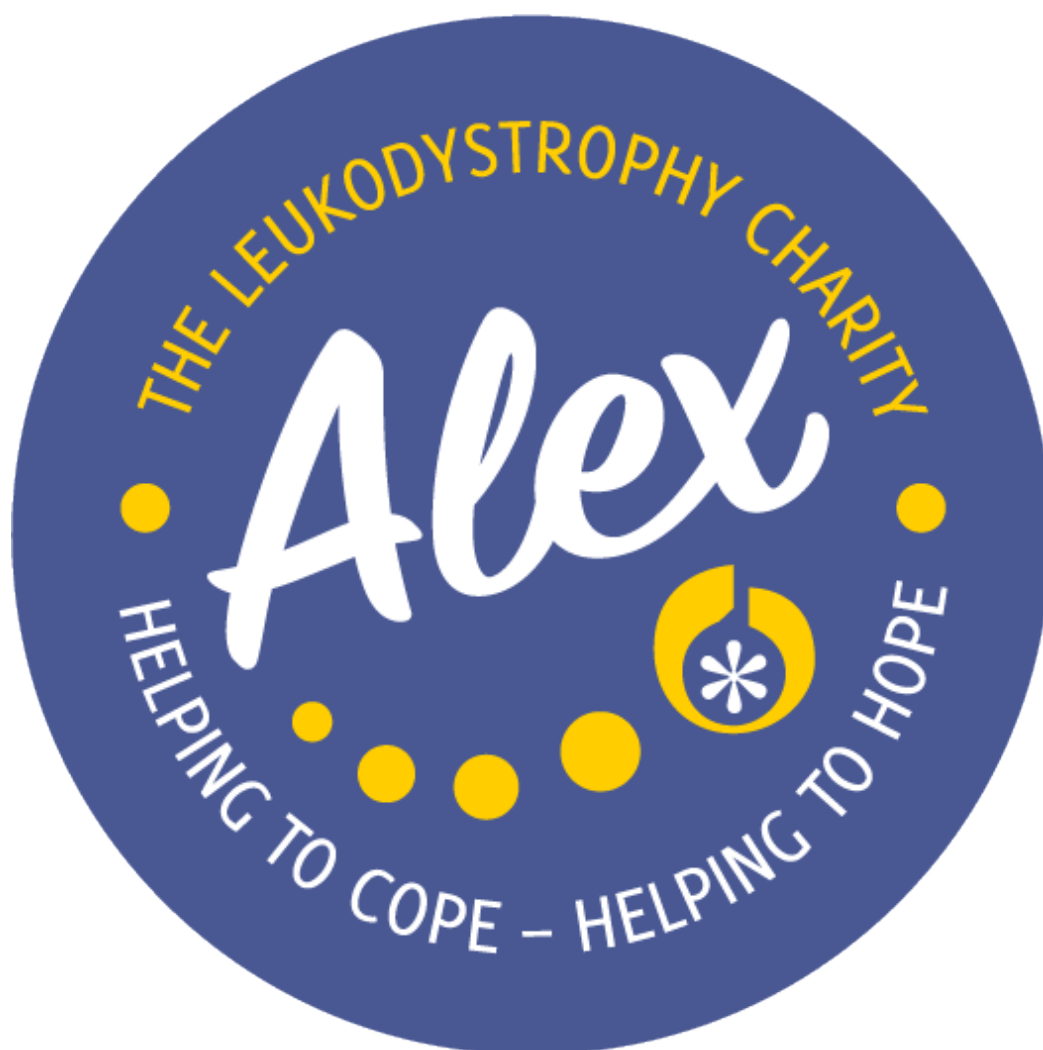




Alex TLC
Community Weekend
2025 Report

Executive summary

Our Community Weekend continues to be a cornerstone event for the Alex TLC community, bringing together individuals and families affected by leukodystrophy alongside clinicians, researchers, and industry partners. The 2025 event saw our highest attendance to date, reflecting the growing reach of our community and the increasing need for shared spaces of support and learning.

This report summarises feedback from beneficiaries and professionals who attended the weekend and completed our post-event survey. A majority of attendees described the event as valuable, with all respondents stating they would attend again. Many shared that connecting with others living with or caring for someone with a leukodystrophy helped reduce feelings of isolation and strengthened their sense of community. The programme of presentations, workshops, and discussion groups was widely praised for being informative, relevant, and supportive.

This year marked the second running of our dedicated Science Day in partnership with Leukolabs. The format once again proved highly successful, offering professionals a focused forum to share research, explore clinical developments, and network across disciplines. Professional attendees expressed strong enthusiasm for the continuation of this model and noted that the combined weekend provided meaningful insight into the lived experience of families.

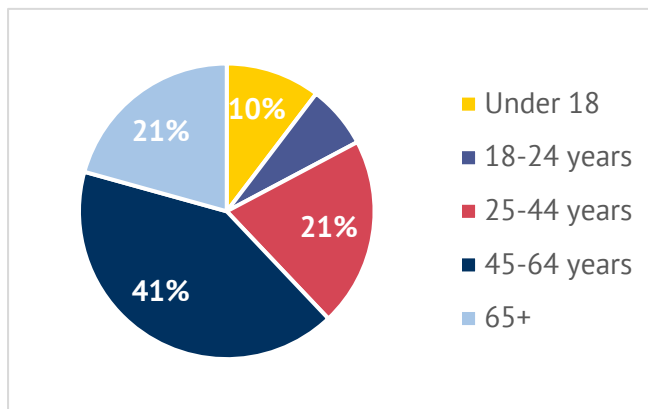
Feedback from both beneficiaries and professionals continues to guide the evolution of the Community Weekend. The insights gathered in 2025 highlight the areas where our approach is working well, while also identifying opportunities to enhance accessibility, content relevance, and connection-building at future events.



Community Weekend 2025 attendees

Demographics

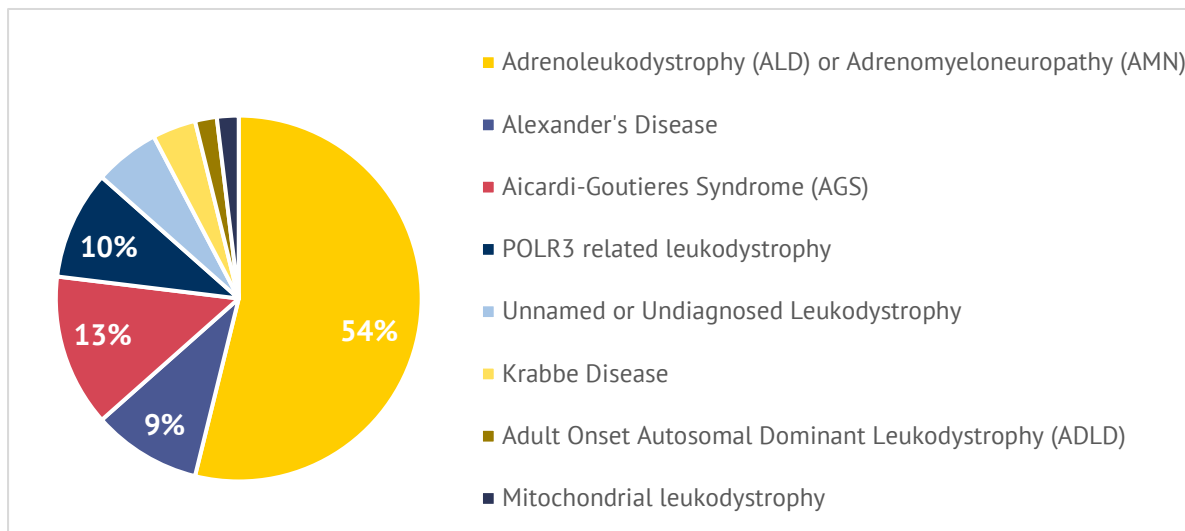
Which age range best represents you?



Our Community Weekend 2025 welcomed 190 attendees. This comprised of 143 beneficiaries, 22 professionals, 9 pharmaceutical company representatives, and 16 Alex TLC staff and volunteers. The responses received in this survey came from individuals and families affected by leukodystrophy who attended the 2025 Community Weekend as well as professionals in the leukodystrophy landscape. The majority of respondents were between 45-64 years of age.

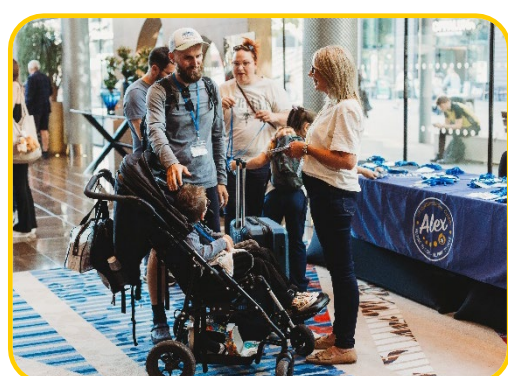
Adrenoleukodystrophy (ALD) and Adrenomyeloneuropathy (AMN) are the most common leukodystrophies affecting 1:14,700¹. 54% of Community Weekend attendees were affected by ALD/AMN which was expected due to the incidence rate, with a selection of rarer leukodystrophies comprising the remaining 46%. There were 8 different leukodystrophies represented at this year's event compared to 7 last year. Of these 8 conditions, 4 were rarer types of leukodystrophy, which included unnamed/undiagnosed, ADLD, Krabbe and Mitochondrial disease. This reflects an increase in the number of families joining the charity affected by rarer leukodystrophies, perhaps influenced by additional referrals from the new NHS England Inherited White Matter Disease (IWMD) Service.

Type of leukodystrophy affecting attendees



¹ References

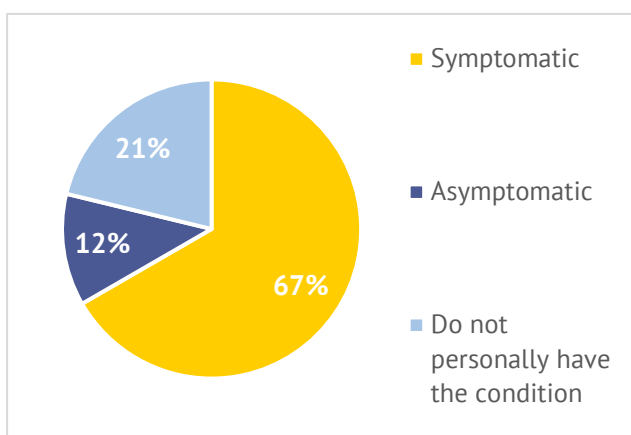
1. Moser, A. B., Jones, R. O., Hubbard, W. C., Tortorelli, S., Orsini, J. J., Caggana, M., Vogel, B. H., & Raymond, G. V. (2016). Newborn Screening for X-Linked Adrenoleukodystrophy. *International journal of neonatal screening*, 2(4), 15. <https://doi.org/10.3390/ijns2040015>



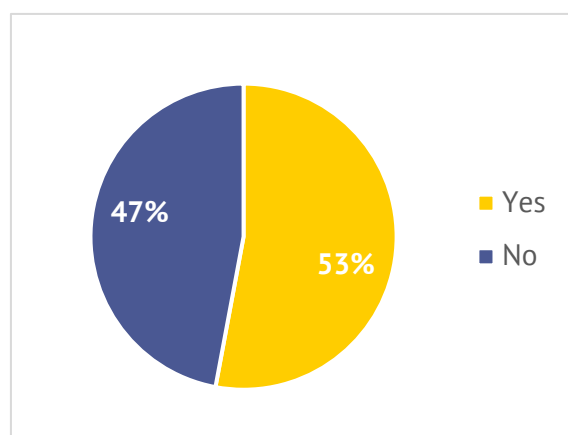
67% of respondents had symptoms of leukodystrophy, this is a decrease in symptomatic respondents compared to the previous year's 84%. We achieved a slightly higher total number of responses this year (36 vs 31) with the additional responses mainly going into the non-symptomatic categories thus resulting in the notable change in the symptomatic percentage. The number of symptomatic responses was similar across both years whereas the number of non-symptomatic was slightly higher than last year.

53% classified themselves as carers which was similar to the previous year's 58%. The majority of carers have symptoms of a leukodystrophy themselves (61% data not shown).

How are you/the person you represent affected by your condition?



Are you caring for someone with a leukodystrophy?



Community Weekend attendance

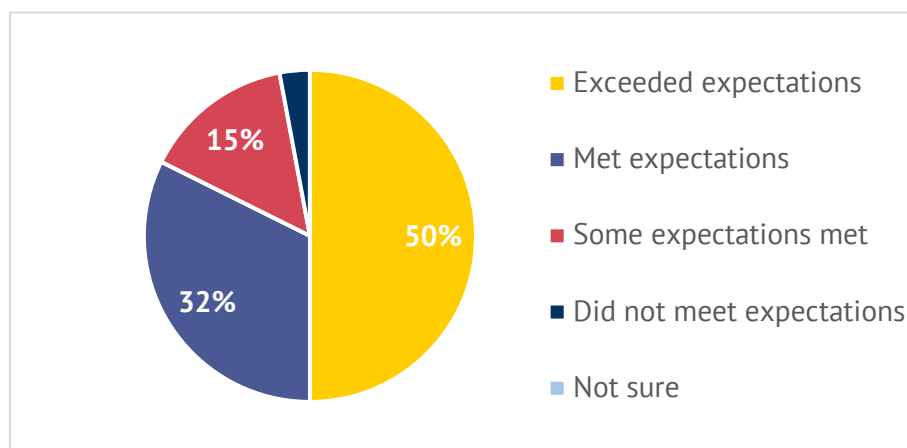
The majority of attendees found out about the Community Weekend from Alex TLC directly either through our socials, emails, or website and some attendees found out about it from another family in the community or a health professional.



Most respondents said their reasons for attending the event was to meet up with old friends, make new ones, learn more about their condition, meet leukodystrophy professionals, and hear updates on research. *“As a family, we have been searching for solutions to the medical condition we are facing, but we often found that the information available elsewhere was very limited. That’s why we decided to participate – to learn more, gather knowledge, and meet people who truly understand what we are going through.”*

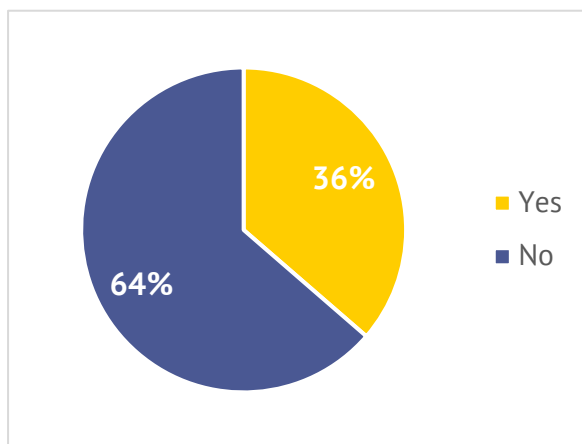
The majority of respondents said the event met or exceeded their expectations. One respondent reported that their expectations of the event had not been met but did not directly explain why, though in other comments they mentioned struggling to interact with others as it was their first time and other attendees seemed to already be sat in groups or with people they already knew. They were unaware of our pre-event meetings designed to help attendees connect. During the event, we do our best to encourage interaction and make sure no one is left sitting alone. However, since people arrive at different times, it can be challenging to manage how relationships develop.

Did the event meet your expectations?



This was the first experience of our Community Weekend for 36% of attendees while 64% had attended one previously. This is the same as last year and a positive sign that we continue to have returning attendees as well as reaching new families and individuals. One respondent who attended for the first time said, *“This was our first community weekend, so to listen to and share personal experiences with others on the same journey has been inspiring. To realise we are not alone is comforting and to know that we can reach out to Alex TLC in the future for support is reassuring. I would like to thank Alex TLC for the invitation to a very rewarding weekend and we look forward to next years event.”*

Was this your first time attending a Community Weekend event?

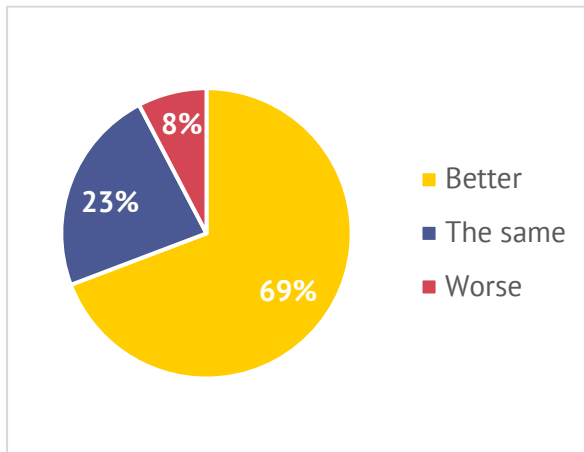


Other comments about the event:

- *“The weekend is such a great opportunity to hear from researchers/doctors and to meet others affected by the same condition as me and my family. The weekend is always so uplifting and always enjoy it.”*
- *“It is wonderful to connect with people and feel part of a community. It can be a lonely little understood journey and the weekend transports you to a place where people ‘get it’ and genuinely care. That is a refreshing breath of fresh air and you feel validated and held.”*



How do you feel this event compared to previous Community Weekend(s)?



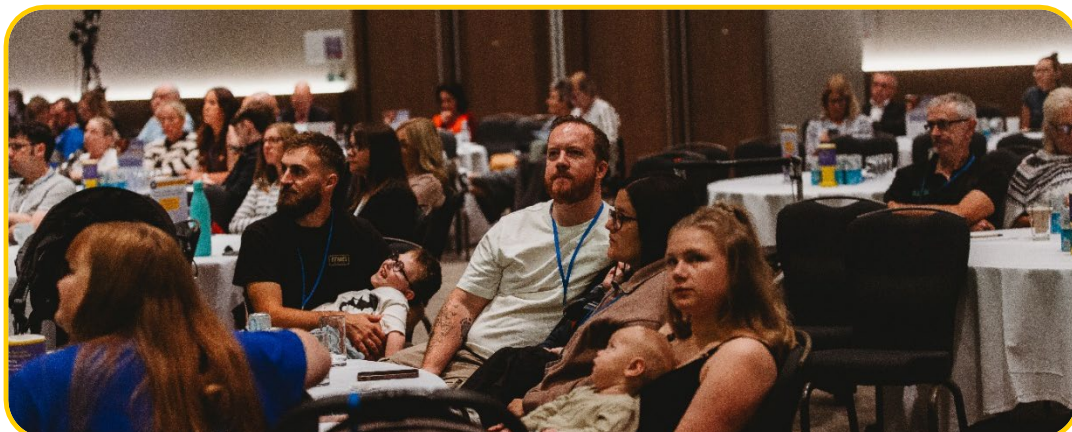
Those who had previously attended our Community Weekend(s) said that it was either better or the same as previous events. *"There were so many great speakers, especially talking about females with AMN. The hotel was fantastic...The staff were really friendly and helpful and the food was lovely."* There was a significant increase in those who felt it was better (69%) than previous Community Weekends compared to last year (40%) which is great to see that we are continuously improving our events.

Two respondents reported the event was worse, due to less doctors being present than in previous years (21 compared to 33 last year), but those respondents still enjoyed the event and found it rewarding. *"I was disappointed that there were not more professionals from the US as there usually would be (just unfortunate clash of events). Hence there was less about research this time. However, hotel and food were great and attending was rewarding."* At this year's event we had more condition management presentations as requested by community members in previous Community Weekend surveys. We hold our event on an annual basis and as leukodystrophy is such a rare disease, there are some years when there are less research developments to provide updates on.

Other respondents that attended previously stated:

- *"I think the venue was great and the staff [were] really helpful and attentive. We heard from speakers who hadn't been previously - particularly got a lot from the women and ALD session on the Sunday -...The children's activities were also great and seemed to really engage the children."*
- *"Much more space in the conference rooms made everything much easier on my scooter. The food was better and the whole conference space in general was really good."*

Taking feedback into account from the previous year we made sure the venue had further space for attendees including between tables, there was also a nice balcony area for fresh air with seating and other seating areas around the venue for attendees to relax and socialise.



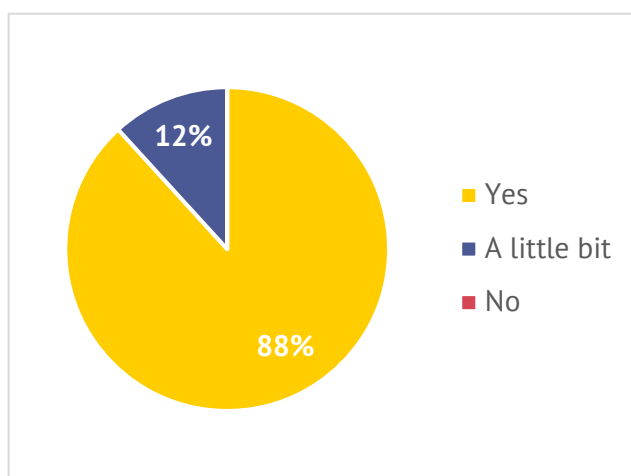
Community Weekend experience

We design the event to encourage meaningful connections between attendees. When asked whether the event activities helped attendees to connect with others, 88% of respondents felt they did. They enjoyed being able to meet new people as well as see those they have met before and have a shared understanding of what they are going through, *“...To share experiences is invaluable and the weekend makes you feel that you are not alone in having to cope.”*

Respondents described how the event helped them make connections:

- *“For example after the women with ALD talk a group of us stayed on to talk about what we have in common etc, advice which was very helpful”*
- *“Because of the way the weekend is designed, it’s always easy to connect. This year - with the help of Hilton Wembley big spaces - it felt even easier.”*
- *“It would be nice if the discussion group was earlier on in the weekend, as it seems a shame to have deep conversations and then just leave - rather than being able to extend those conversations and continue getting to know the people during the weekend!”*

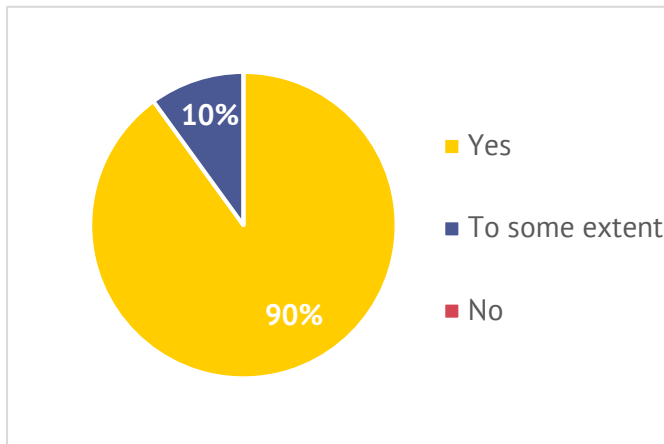
Did the event activities help you to connect with others?



As the discussion groups were thoroughly enjoyed and valued by respondents, we will look into accommodating them earlier in the schedule next year to allow attendees that early connection and ability to develop them further throughout the weekend.

We provided two opportunities where attendees could meet others before the event started, one online meeting prior to the event and a pre-dinner meeting on the first night of the event. There were over 20 respondents who attended these with all having found it useful. Most respondents had not used it and 32% did not know about it. We will ensure that we improve attendees' awareness of welcome meetings by sharing details further in advance.

Did meeting other people with a leukodystrophy at the event help you to feel less alone in your situation?



One of our main goals with the Community Weekend is to help attendees meet new people and make connections that help them feel less alone. All respondents said meeting other people with a leukodystrophy at the event helped them to feel less alone in their situation, this was similar to last year's results. One respondent shared, *"It is isolating when normally you don't meet people with a leukodystrophy. There is no need to explain the condition, only how it affects you and there is a feeling that we all have something in common. Also it is great*

to see people laughing and enjoying themselves despite everything."

Other respondents said:

- *"It's hard to explain, everyone just gets it, no explanations just acceptance and love. I also adore how much love is shown to the boys and how all the siblings interact and keep the event inclusive making sure all are included."*
- *"Every year we discover more similarities that we have with other families, and it puts our life into a lot more perspective."*
- *"It's brilliant not having to feel 'rare' for a weekend..."*

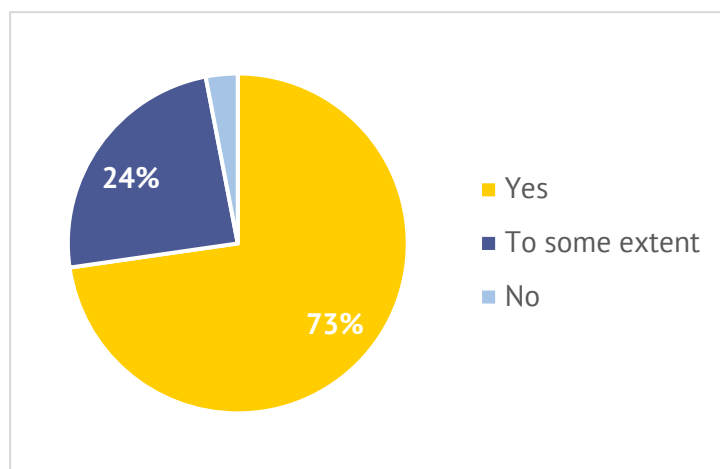


Content

An important aim of the event was to increase attendee's understanding of their or their loved one's conditions, ongoing research, and treatment options through the various presentations and workshops. A majority of attendees said the information shared during the event increased their understanding of these areas, which was similar to the previous year.

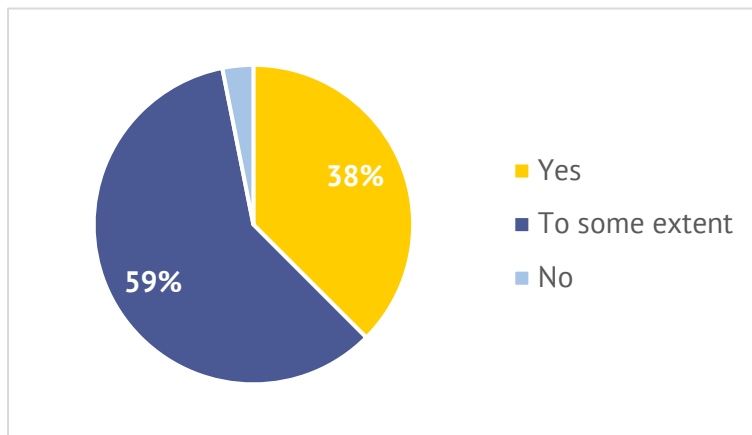
- *"I found out so much positive research development, especially during the break sessions where I had the opportunity to chat to some of the research clinicians and doctors."*
- *"The presentation about bowel and bladder was really helpful and I feel informed to request next steps for my treatment. The presentation for women with AMN was validating and insightful..."*
- *"By participating in this event, we were able to enrich our knowledge in so many meaningful ways. The positive interactions with medical professionals, where we could exchange views and ask questions under one roof, were truly valuable. Equally, making new connections with other families in similar situations was both helpful and encouraging, giving us the chance to share experiences and feel supported."*
- *"The presentations were great and the doctors were good at answering questions and explaining leukodystrophy in a non-scientific way."*

Did you find the information shared during the event increased understanding about your/loved one's condition, research, and treatment options?



One respondent with a rare leukodystrophy reported no to this question and said, *"Nothing too specific to our leukodystrophy."* We do our best to include relevant presentations for all attendees at the event, but not all individuals may feel the information is specific to their condition. Unfortunately, the rarity of leukodystrophies does impact the progression of research and treatment advancements, so there may not always be relevant updates for all leukodystrophies.

Do you feel the guidance (presentations/workshops) during the event will help to improve management of your/a loved one's condition?

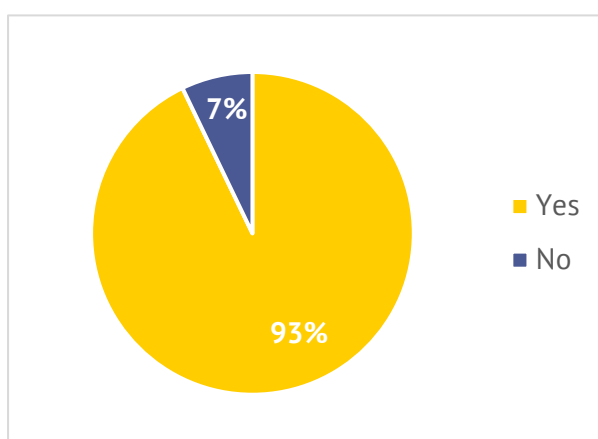


many tips to help with stress, depression and pain."

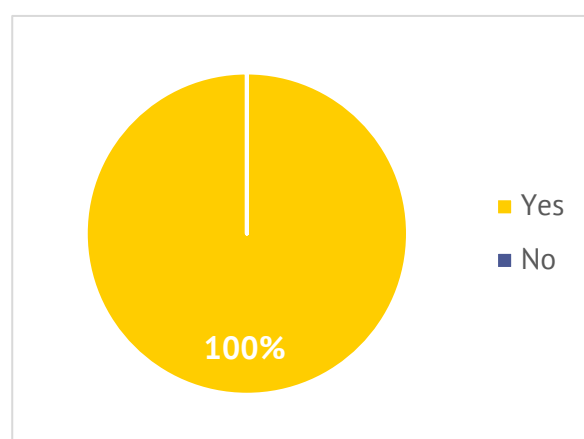
We aim to help attendees improve management of their or their loved one's condition through the guidance provided in our presentations and workshops. All but one respondent reported the guidance will help to improve condition management, *"The more knowledge we have allows us to make better informed decisions and allows us to ask challenging questions to those who care for [our loved ones]"*. Another respondent said, *"The wellbeing talk gave me so*

Overall, respondents were very positive about the presentation and workshop content, with 93% and 100% respectively finding them useful. One respondent said, *"Complex subjects professionally presented in an understandable way without any element of feeling patronized."* Another respondent shared about one they found particularly informative saying, *"Dr Lydia Greens talks were amazing and very much to the point with lots of honesty and also Dr Dipak Rams talks was very informative and I feel I will benefit in the future with the information I've learned."* The workshops had positive feedback and were found to be informative, with one respondent saying that the, *"IWMD session with Jade explained the purpose of the register very clearly."* As with previous questions, one respondent with a rare leukodystrophy answered 'no.' As noted earlier, the rarity of certain conditions can limit research progress and slow advances in treatment.

Overall, did you find the presentation content useful?



Overall, did you find the workshop content useful?



We asked about any other workshops or presentation topics they would like to see at future events and there were some consistent themes including physical therapy, occupational therapy, equipment, and exercise. Some other suggestions were, *"Emotional impact of symptoms on a relationship"*, grief and family counselling, and *"Maybe a workshop on the help and benefits that are available"*.



Other suggestions included:

- *“Human element - hearing about each others stories. Or a general Q&A with a bunch of the doctors in the room (never feels like enough time at the end of the sessions).”*
- *“...Wheelchairs services... any companies that would talk around what can be provided ... maybe whizz kids...”*
- *“...I attended a hospice planning day a few years ago and took part in a whose shoes (I think!) table exercise which was so good for all involved in discussing and sharing but also got people together”*
- *“A longer workshop with affected families possibly with a specialist present. These discussions provide first hand information and advice which are extremely helpful and essential for carers.”*
- *“Peer led discussion time would be useful”*
- *“Maybe a workshop on the help and benefits that are available”*
- *“More practical stuff about managing/ improving day to day life. For example: equipment/ lifting/ more info on peer support connecting with others and families.”*

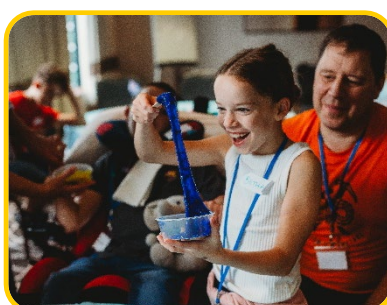
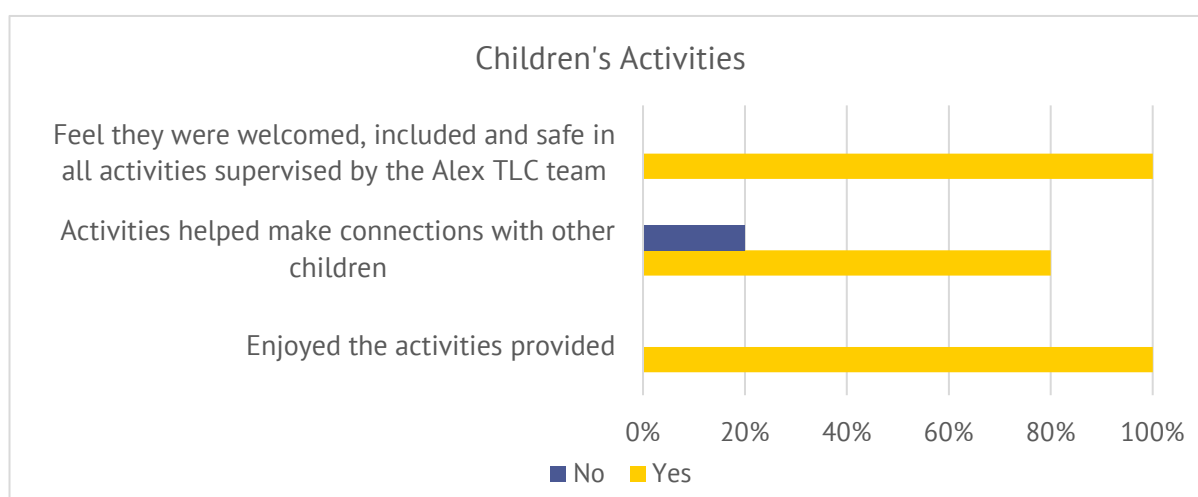
These are all great suggestions that give insight into what our community is interested in and will be considered when deciding the next Community Weekend content.

Children's activities

The Alex TLC team provided supervised children's activities throughout the Community Weekend to provide children and young people a fun environment and chance to make connections while giving parents the space to focus on the presentations and workshops. 32 children attended and really enjoyed the children's activities. *"My daughter loved the activities and had the best time!"* Another respondent shared, *"Animals were fab! The boys enjoyed all the activities."*

We asked respondents what the best part of the Community Weekend was for the children in regard to building relationships. One respondent said, *"Making new friends and reconnecting with old ones. No judgements, just fun and laughter."*

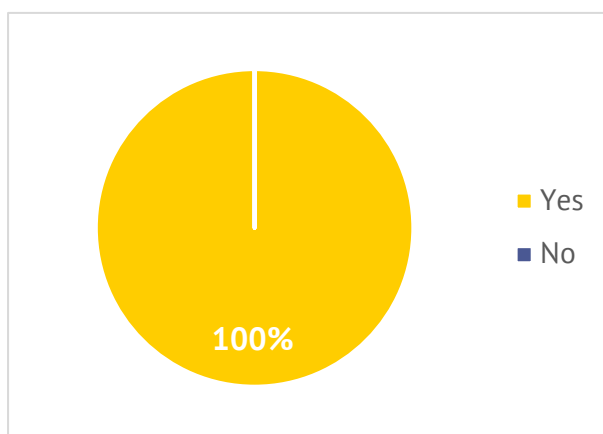
Most respondents felt the activities helped their child/children make connections with other children at the event. All respondents felt their children were welcomed, included and safe in all activities supervised by the Alex TLC team, with one respondent saying, *"Staff with the kids were amazing as always!"*



Overall impact

All respondents felt the event was useful for those affected by leukodystrophy, *"This was my first time attending this event with my family, and we are very glad we took part. We have long been searching for solutions to our medical issue, but information elsewhere has been limited. Here, we gained valuable knowledge, with comprehensive presentations tailored to our needs. The chance to interact with medical professionals under one roof and connect with other families in similar situations was both useful and reassuring. We especially value the knowledge we can now use to better handle the condition of our family member. We enjoyed the event very much."* It is very rewarding to see the positive and profound impact our Community Weekend has for our beneficiaries and continues to motivate us to provide these important connecting opportunities.

Overall, did you feel the event was useful for those affected by leukodystrophy?



Some final comments about the Community Weekend:

- *"A huge thank you to everyone for making this weekend possible, we don't get the opportunity to get away so this weekend was wonderful and to spend it with such lovely people made it even better."*
- *"Thank you so much for another amazing weekend! It's become something we look forward to. All at Alex are wonderful people and the other families were lovely! Thanks to Alex TLC we have made some friends for life x."*
- *"It was great that there was a mixture of talks about different leukodystrophies...Overall, we had a great weekend, thank you Alex TLC."*
- *"On the last day being in a small group and being able to talk to people with lots in common"*



Professionals

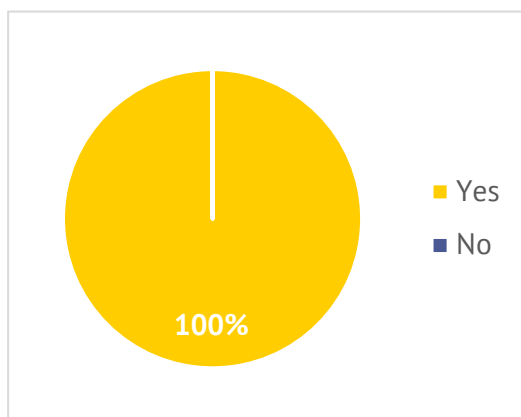
Science Day

This was our second Science Day in collaboration with Leukolabs. There were 58 attendees consisting of researchers, PhD/post-doctoral students, doctors and pharmaceutical employees. This provided professionals with an interest in leukodystrophy an opportunity to meet, interact and present their research and clinical information to other professionals. This also helped to keep the focus of presentations during the Community Weekend relevant for beneficiaries. There was very positive feedback about the event, *"I don't know what i liked most. It was just a great day and very nice program. Very well done! Great it's connected to the family weekend."*

All professional respondents found the event useful.

- *"People from different fields bring me lots of new ideas! Love it!"*
- *"Good mix of basic science and clinical application.; Networking, high quality presentations."*
- *"Educational and interactive sessions, with collaborative work between scientists and clinicians!"*
- *"I learned a lot from the presentations"*

Did you find the Science Day useful?



The layout of the Science Day last year received very positive feedback, so the three sessions were maintained, a clinical session, UK leukodystrophy research, and clinical trial updates from industry partners. There was also an inspirational speaker: Professor Ragnhildur Thóra Káradóttir, the director of the MS Society Cambridge Centre for Myelin Repair, who presented her work on myelin regeneration. The majority of professional respondents found all of the sessions useful.

- Clinical session: *"I appreciated especially the outcome measures talk which was applicable to many LDs. The other talks were excellent as well good to start out with clinical focus"*
- Inspirational speaker: *"It was an amazing and interesting talk, and I think it's so important to be able to translate information and knowledge between different disorders and pathologies that may have similarities."*
- Leukodystrophy research session: *"Good session, lot of interesting stuff"*
- Parent representative speaker: *"Excellent to hear a parent perspective as a lab scientist. Very effective video"*
- Clinical trial updates from industry partners: *"Very informative and hopeful."*

One professional respondent suggested, *“Slightly longer for the posters would’ve been nice but on the whole really well organised”*. We will feedback this suggestion to the team when planning the next Science Day and its content.



Community Weekend

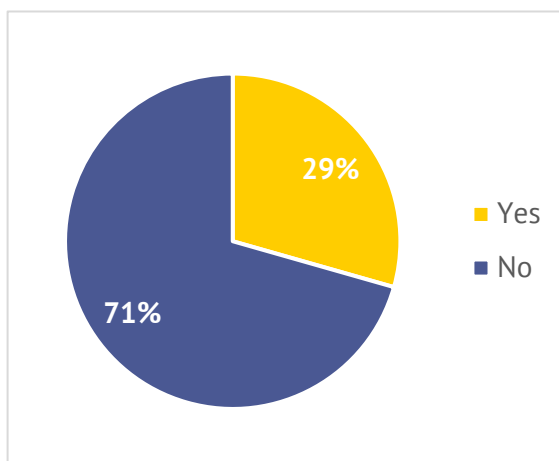
This year 48 medical and research professionals, 9 pharmaceutical company representatives attended our Community Weekend. Their work is based in different countries with the majority based in the United Kingdom, 12% based in the United States, 8% based in Spain and 6% in Netherlands.

There was very positive feedback from professionals and it was the first Community Weekend for 29% of professional respondents. All said they would attend again. One professional respondent shared, *“I like everything that Alex TLC does for the leukodystrophy community, and I am happy to help. The atmosphere at the meeting is great. There are good presentations and an excellent location (and food). Combining the weekend with the science day is super. It’s close by and easy to travel to. It’s nice to meet families and friends.”*

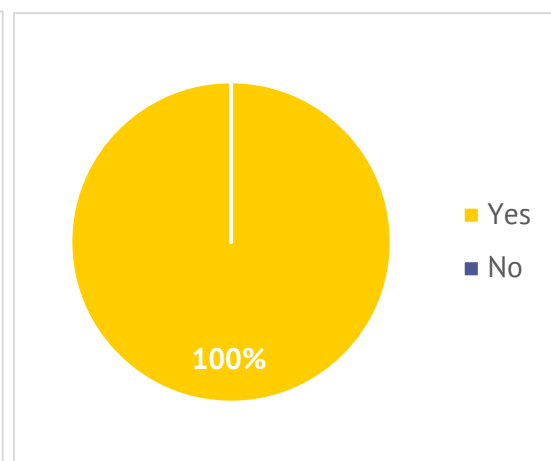
Other professional respondents said:

- *“I value the opportunity to meet people living with leukodystrophy and speak with them, their caregivers, and families about what’s important to them. I also enjoy the chance to hear what’s on the mind of scientists and clinicians - I always leave this conference with new ideas!”*
- *“I always enjoy the community weekend; chance to meet my colleagues and patients/parents as well as the lovely ALEX TLC team in person”.*

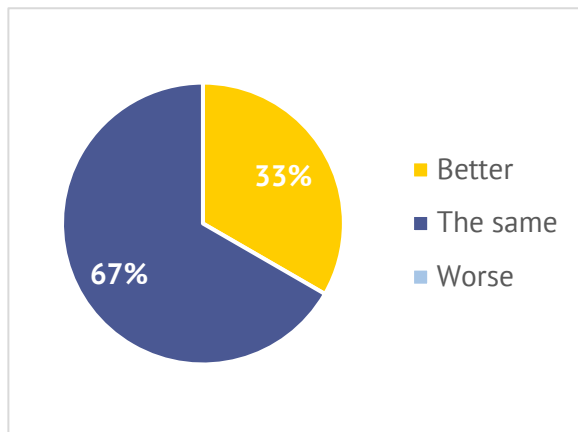
Was this your first time attending?



Would you attend again?



How do you feel this event compared to previous Community Weekend(s)?



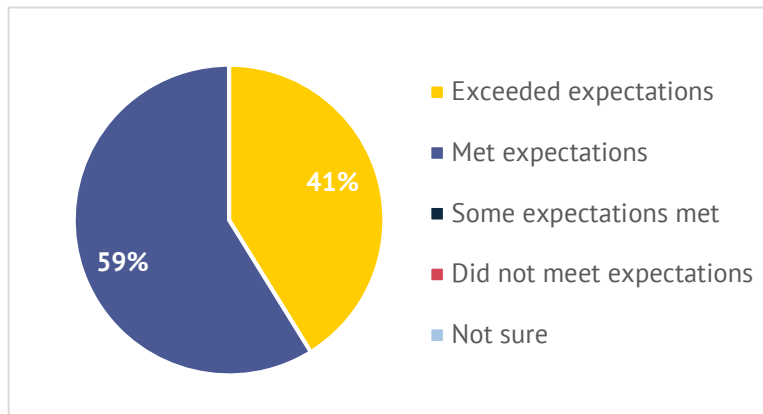
All professionals who have attended before thought the 2025 Community Weekend was better or the same as previous events.

- *“It was of similar quality overall for me. The one area it was better was the venue.”*
- *“Venue was great. Good variety of themes presented.”*
- *“The previous year was excellent as well. The combi with the science day is brilliant”*

Professionals attended for several reasons, meeting other professionals and families of those affected by a leukodystrophy were most

prevalent and the majority of professionals were presenting at the event. Several were interested in learning more about the work of Alex TLC. Based on their reasons for attending, all said the event met their expectations and 41% said it exceeded them. One professional respondent said, *“The location was perfect, the rooms were perfect, and the conference rooms were great. The audio and presentations went very smoothly. Slido was fun. The entertainment was fun. The food was excellent. No complaints here!”*

Based on your reasons for attending, did the Community Weekend meet your expectations?



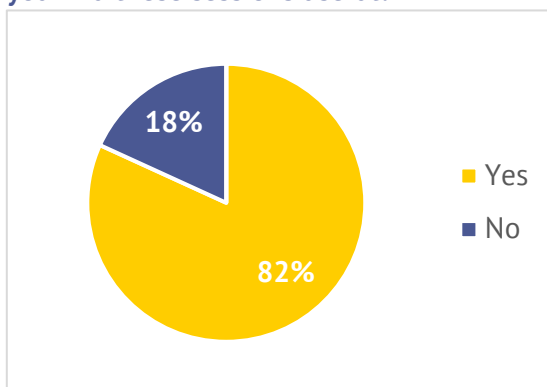
Community Weekend content

There were two roundtable sessions, one covering newborn screening in the UK and another on rare diseases. All professionals that participated in a roundtable found these sessions useful and provided very positive feedback on them.

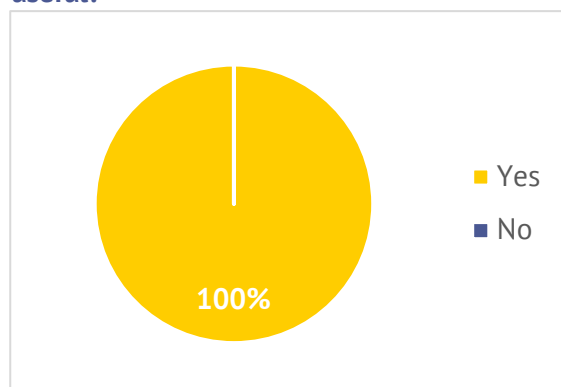
- *“Useful to hear what others are doing in this area of research.”*
- *“Got a lot out of the NBS round table, useful dialogue with international colleagues”*
- *“good way to share ideas”*

All professionals found the presentation content throughout the Community Weekend useful, *“Lots of variety and very interesting.”* There was a comment about trying to limit having to switch between rooms for presentations and some in the side room being quite popular, *“Side room was packed for AGS and symptom management sessions. For the latter might be worth splitting out from one talk to multiple on different symptoms (e.g. have one talk/workshop for just bladder management rather than it being combined with other symptoms).”* We were pleasantly surprised by the number of attendees for some of the presentations and will look into how best to split and schedule presentations and workshops.

If you participated in a Roundtable, did you find these sessions useful?



Overall, did you find the presentation content useful?



Overall

Overall, the 2025 Community Weekend was thoroughly enjoyed by the professionals *“This is an amazing event for professionals and families, it is really important it continues. The families look forward to it all year, they build support relationships that would not happen without it. Well done”*.

Some other professional feedback comments include:

- *“The event was great this was my first time. I would love to come back and present meaningful information to patients. I believe I have a better idea of what those effected would like to hear or see presented. I think there should be a planning meeting with those invited so we can be well prepared in advance.”*
- *“I really admire all your work at Alex TLC and it is very much appreciated.”*
- *“I would like to see a greater variety of presenters maybe from other professions within the mdt - psychologists, therapist etc”*

- *“Always a challenge to cater to the needs of all the diverse patient populations/ different leukodystrophies - might be useful to consider having tailored content for different groups as part of future events?”*

Our Community Weekends are an annual event providing opportunities for different specialists to attend each year. we remain committed to securing a diverse group of medical professionals for our events.

The number of beneficiaries in our charity has grown significantly over the past year, particularly among individuals affected by rarer leukodystrophies. In response, we have expanded the Community Weekend's content to reflect the broader range of conditions represented, ensuring the information we provide is relevant to as many attendees as possible. We will continue this approach at future events.



Lessons learnt

Based on feedback from our previous event, the following table summarises lessons learnt from our 2024 Community Weekend and how we used this to shape our 2025 event.

Issues Identified in 2024	Response Implemented for the 2025 Community Weekend
Venue accessibility challenges: limited space between tables, difficulty navigating with mobility aids, toilets on different floors, limited quiet/private spaces.	Improved venue layout with larger rooms, wider spacing, accessible movement routes, balcony and lounge areas for conversations, and better overall flow.
32% unaware of Buddy system and pre-event connection opportunity.	Introduced two pre-event meetups (online session + pre-dinner gathering) with better promotion and participation from over 20 attendees.
Desire for more practical condition management content including symptom management, daily living strategies, mobility aids, mental health support.	Added more symptom-focused and wellbeing sessions, including bladder/bowel management, wellbeing talks, IWMD register session, and more practical discussions during workshops and peer led discussion groups.
Presentations too technical or overwhelming for some attendees; need to separate professional and family content more clearly.	Continued dedicated Science Day for professionals; revised family sessions for clarity; fewer total presentations to prevent overload; improved speaker guidance on accessibility of language.
Need for more opportunities to build connections in the weekend.	Scheduled discussion and social connection opportunities earlier, including the return of Friday evening activities and pre-event meetups.
Requests for more content relevant to rarer leukodystrophies.	Added presentations representing more conditions than ever before (4 additional rare types). Facilitated rare-LD discussions.
2024 discussion groups sessions sometimes drifted off-topic.	Improved facilitation and structure for 2025 discussion groups; attendee feedback reflected smoother, more focused conversations.
Navigation and room-switching difficulties including overcrowded workshops and visibility issues.	Selected a more spacious venue, improved room allocation, better screen placement, and anticipated demand for larger rooms (with only a few sessions in the side room exceeding expectations).

Through the feedback gained in these surveys, we can learn from and improve on different aspects of the event for the future. We will do this by taking the following actions:

Lessons learnt in 2025	What we will do the next event
Great feedback from agenda and increased focus on more practical information which beneficiaries would like to see more of.	Review the agenda alongside this report and consider suggestions including condition management, mobility aids, mental health and undiagnosed leukodystrophies.
Some presenters diverted from the topic of the presentation and exceeded their time limit.	Develop a presentation guideline for our speakers.

Mention of more time for reviewing research posters and further engagement of beneficiaries with the posters.	Explore inclusion of a research poster session suitable for beneficiaries.
Discussion groups were at the end of the event and had great feedback from attendees and respondents. They asked to have them earlier in the event.	As the discussion groups were thoroughly enjoyed and valued by respondents, we will look into accommodating them earlier in the schedule to allow attendees an opportunity to develop new connections throughout the weekend.