

ALEX TLC COMMUNITY WEEKEND 2020
IMPACT REPORT

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INTRODUCTION



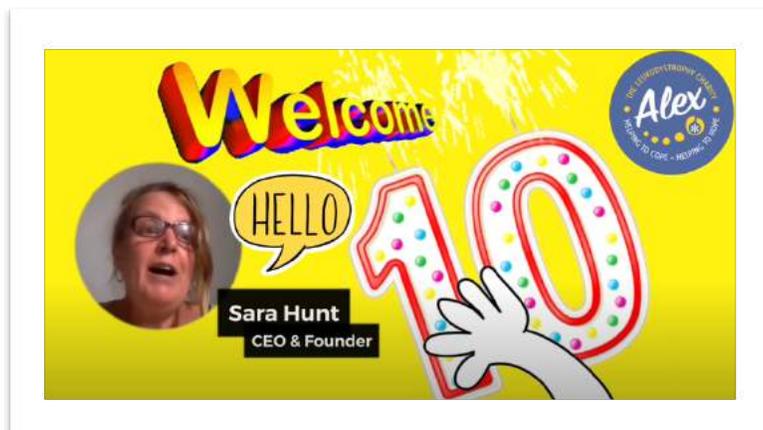
The Alex TLC Digital Community Weekend brings together people affected by Leukodystrophy and their families, alongside doctors, researchers and scientists from around the world to support each other and discuss its impact, patient needs and developments. Normally held in person, this year's event was held online for the first time due to ongoing COVID-19 risks and associated restrictions.

The event gives sufferers and their families the chance to hear treatment updates from and ask questions of leading doctors in the field, as well as talk freely about mutual issues. They were also invited to participate in activities designed to put attendees at ease and encourage interaction, such as doctor moderated networking sessions, a family friendly quiz and a music session from fellow Leukodystrophy sufferer, Max Pahmp. This online event also offered children's activities for all ages and abilities including a creative workshop, a magic show and literature design workshop. It also gives medical professionals the opportunity to hear directly from those affected and presents a rare opportunity to progress research ideas and best practices for treatment.

This year's event was held via zoom on **7th and 8th November 2020**. The 10th Community Weekend saw 2 full days of presentations, networking activities and workshops and was the first time running and hosting an event of this size and online.

There were initially **102 people booked** to come to the event, of which **81 individuals and families with Leukodystrophy** attended, plus **18 doctors**, professionals and leukodystrophy workshop hosts. In addition, there were **5 recreational session hosts** (including mindfulness and a breath workshop) and a further **5 members of staff** attending.

METHODOLOGY



Following the event, attendees were sent a Feedback Survey to gather their views on the weekend. This survey was designed in consultation with CEO (Sara Hunt). It was also influenced by the design of the 2018 Community Weekend Feedback Survey, in order to draw comparisons between responses to the two events, where possible or applicable.

Of the **102** people represented, **14%** completed the survey. This **14%** of survey responses represented **42** individuals and families affected by Leukodystrophy, **41%** of total attendees at the conference

In terms of attendance, there were 56% fewer people in 2020 than in 2018. This is likely due to the ongoing COVID-19 restrictions (and subsequent screen fatigue), as well as a lack of familiarity, desire or ability for attending this type of event online, resulting in lower numbers.

In terms of survey respondents, there were 39% less respondents in 2020 than in 2018 and they represented 29% less of the individuals and families than in 2018. This is likely because of the in person nature in 2018 allowing for organisers to capture participants as they left and personally encourage them to complete the survey. Whereas in 2020, survey feedback was requested at the end of the sessions on the second day as well as via email following the event. It is likely that attendees may have missed, overlooked or forgotten the request to complete the survey.

A recommendation for future events would be to consider increased requests for survey feedback during the event, incentivisation (i.e. asking for survey feedback before a popular session or offering a prize) and to consider quick/ shorter surveys between each of the individual sessions.

“Thank you for an amazing weekend.”

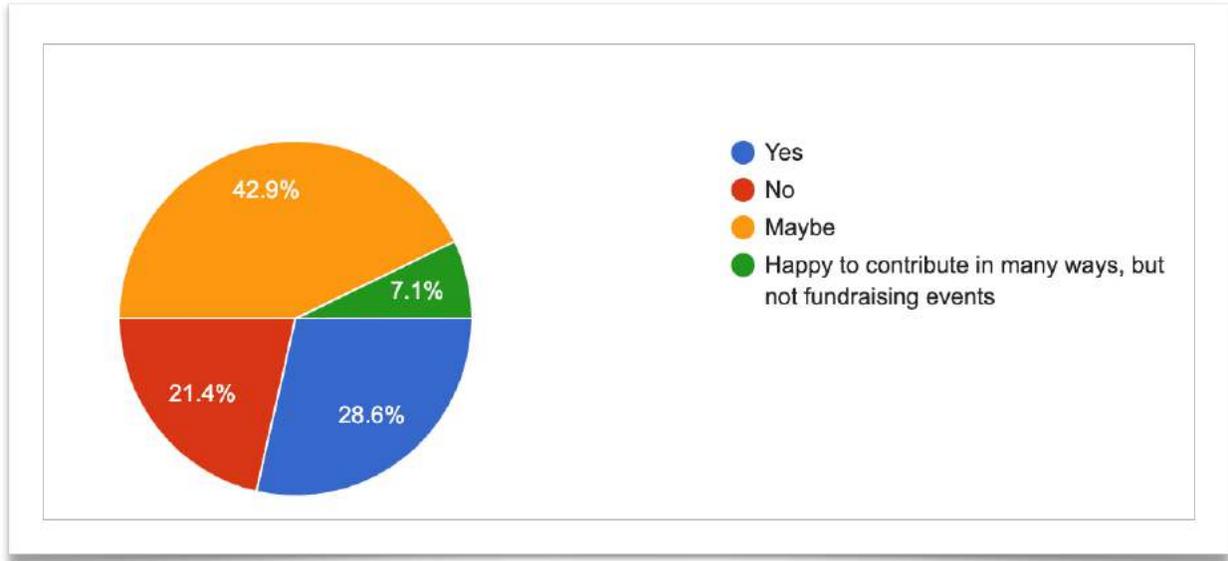
“This digital approach has been just as good as ‘the real thing’. Well done Alex TLC, and thank you.”

Alex TLC Community Weekend 2020, Impact Report

The survey asks respondents questions on demographics and their condition/connection to leukodystrophy, before asking for feedback on the presentations, activities, format and delivery, as well as the event as a whole.

Respondents were also asked about their willingness to support future events through contributions or fundraising. Of the survey respondents; 28.6% stated they would be happy, 42.9% said they might be, 21.4% stated no and a final 7.1% stated that they would be happy to contribute in many ways, but not fundraising.

With more than 70% warm to the idea of fundraising, it would be beneficial to both outline the importance of fundraising for the charity as well as include some ideas or ways attendees can support the charity through fundraising at the event itself. This could include a fundraising session within the event or guidance and challenges for supporters to fundraise at home.



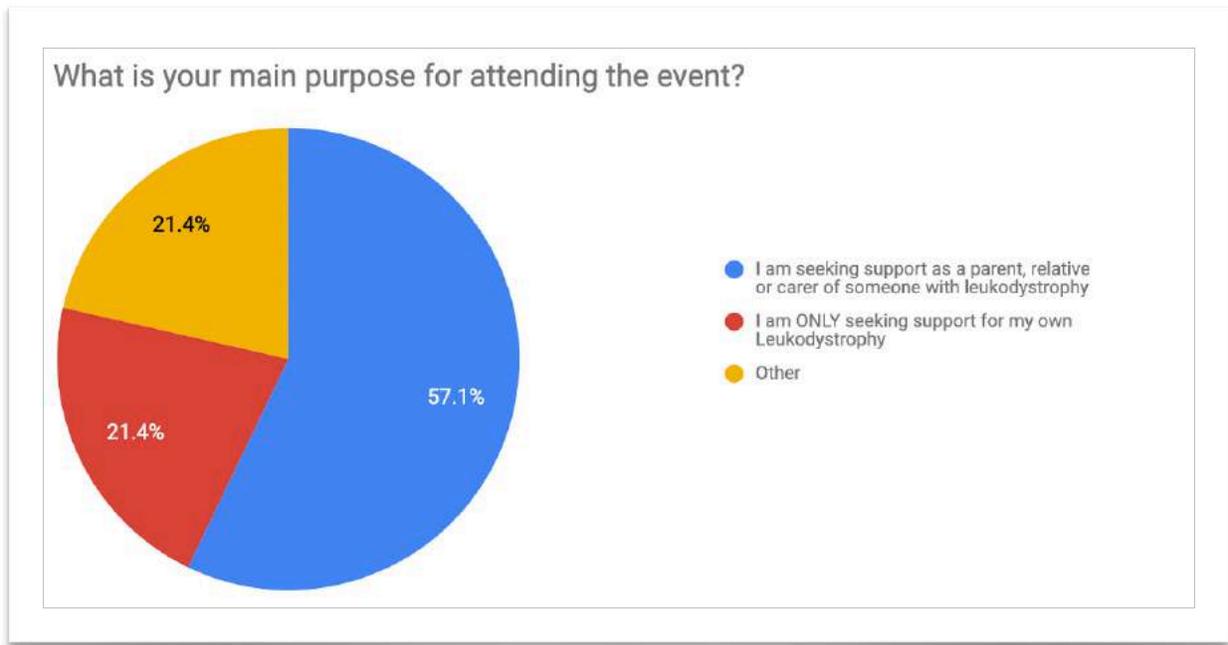
Results of this survey as outlined in this report will be used to make improvements to future events, to attract funding for these events, and for marketing and fundraising purposes. All respondents were asked if comments could be used anonymously for these purposes; and 100% of survey respondents agreed.

DEMOGRAPHICS

Primary purpose for attending:

As shown below, 57% of the survey respondents were seeking support as a parent, relative or carer of someone with leukodystrophy as their primary reason for attending the conference, with 21% seeking support for their own Leukodystrophy. The remaining 21% were attending for other reasons which included specific conditions as well as to hear from professionals, learn of treatments, new trials and drugs.

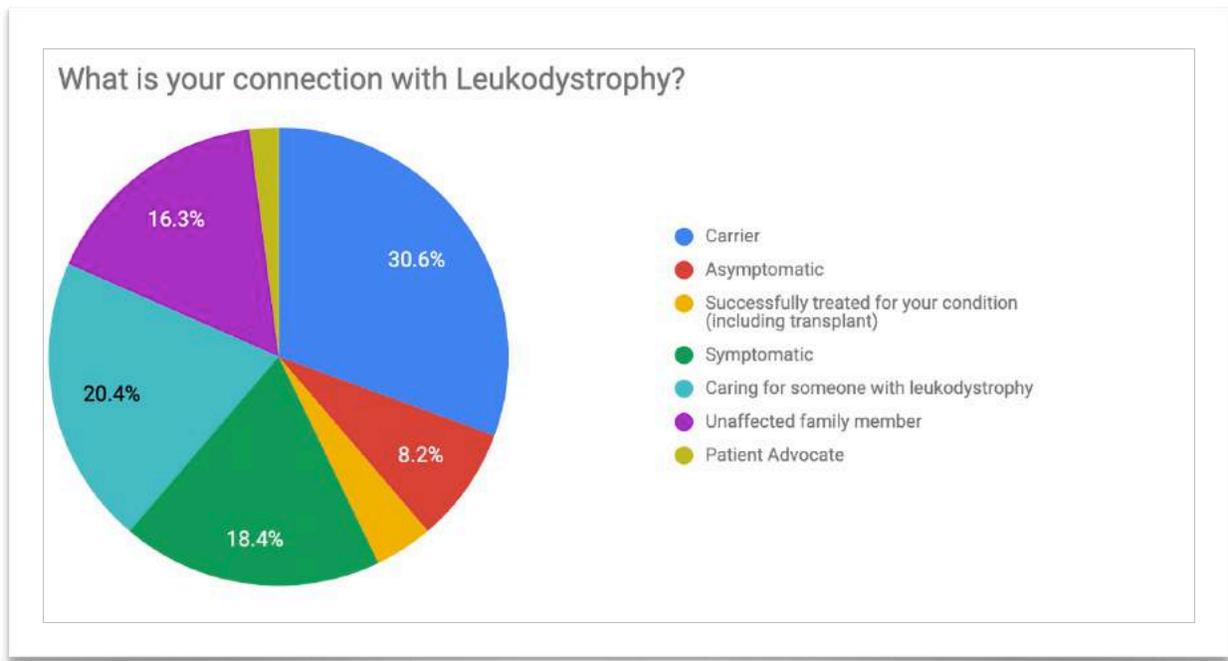
This is a similar profile to 2018 in terms of the top 3 most popular reasons, with the exception of 4% of attendees in 2018 stating that they were seeking support after losing a child or relative with Leukodystrophy whereas no one selected this as their reason in 2020.



Connection with Leukodystrophy

Our attendees are connected with Leukodystrophy in a number of different ways and often represent (or are connected to) more than one person affected in their group or household. Of those affected by Leukodystrophy, we asked survey respondents how many of their group or household (including themselves) fell into categories such as carrier, Asymptomatic and caring for someone.

This was a multiple choice question and most respondents selected several reasons in which their group or household were connected with Leukodystrophy. As you can see from the chart below, the most common connection with leukodystrophy was carrier which reflected 30% of the people represented. 20.4% of those represented are caring for someone with Leukodystrophy and 18.4% of those represented are symptomatic.



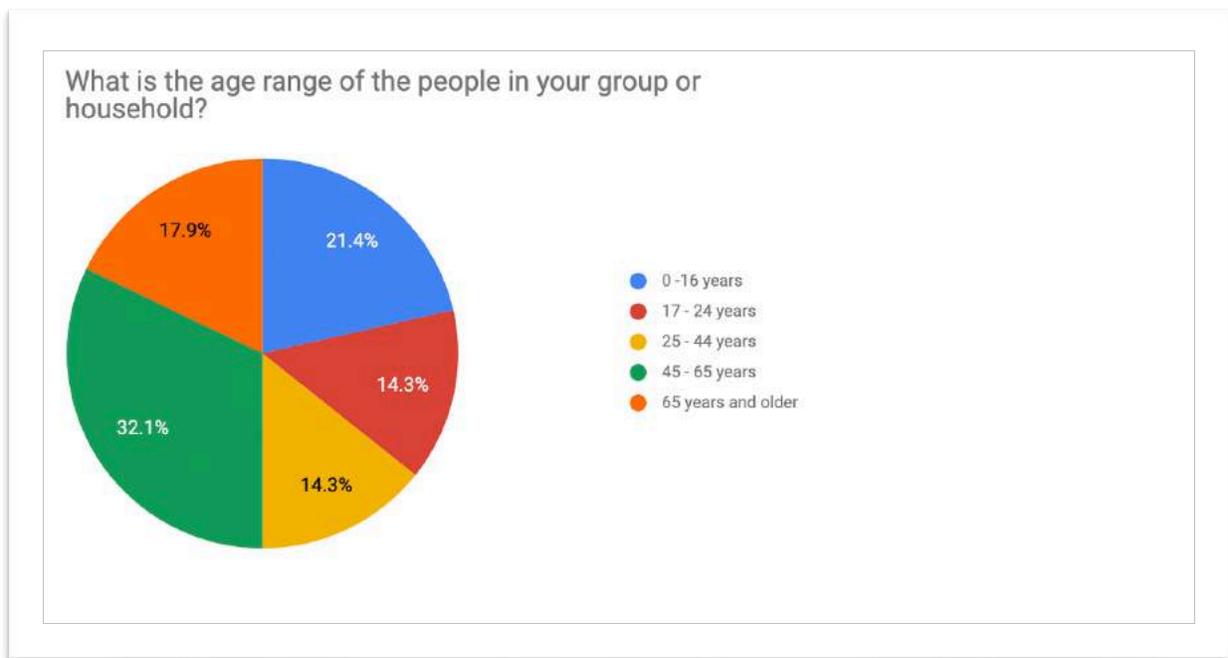
This has some similarity with the responses in 2018, where the 1st and 2nd most commonly selected options in 2020 (carrier and caring for someone) were the 1st and 3rd most commonly selected in 2018; with (female) carriers at 24% and then caring for someone with leukodystrophy at 16%. However, whilst symptomatic was the 3rd most popular selection for survey respondents in 2020 with 18%, it came 5th in 2018 with just 8% of the total.

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Age range

Many attendees joined the Digital Community Weekend as part of a group, particularly those with Leukodystrophy or those supporting others with the condition. In the survey, we asked what the age brackets attendees and the people they joined with fell into.

As you can see from the chart below, people were fairly well distributed across all age ranges, with a small majority (35%) falling into the 45 to 65 years olds. The next largest age group was children with 21% being under 16. 19% were 65 years or older and the final 28% was distributed equally between teens (17 to 24 years) and young adults (25 to 44 years old) with 14% each.

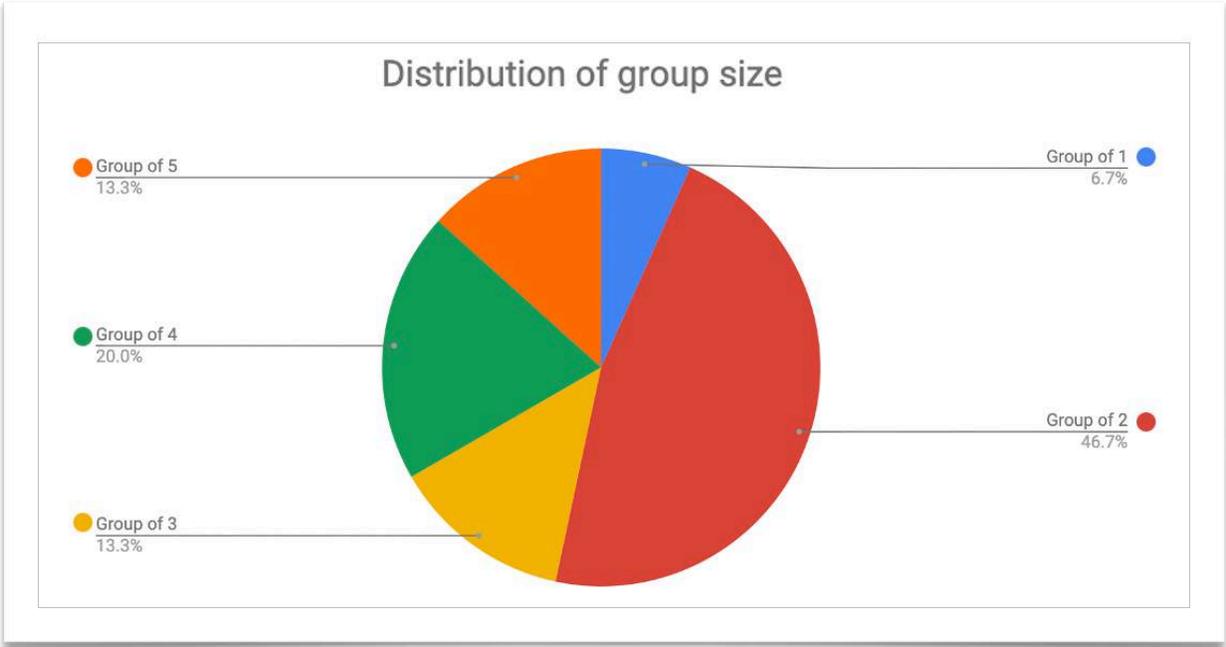


The 21% of survey respondents attending with at least one under 16 year old is 18% greater than the 14% who attended with at least one under 16 in 2018. This increase could be due to the increased accessibility of an online event (attending from home) or an increased technical capability with online tools of this age group. To clarify this, it might be useful to survey beneficiaries to establish whether some virtual events or activities might be more inclusive for this age group for future events.

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Groups

Using the data from the age ranges reported, we can also calculate most common group sizes. As you can see from the chart below, 47% of survey respondents attended with one other person and 20% attended in groups of 4. Only 7% of respondents attended the event alone meaning that 93% of respondents attended the event with one or more other people.



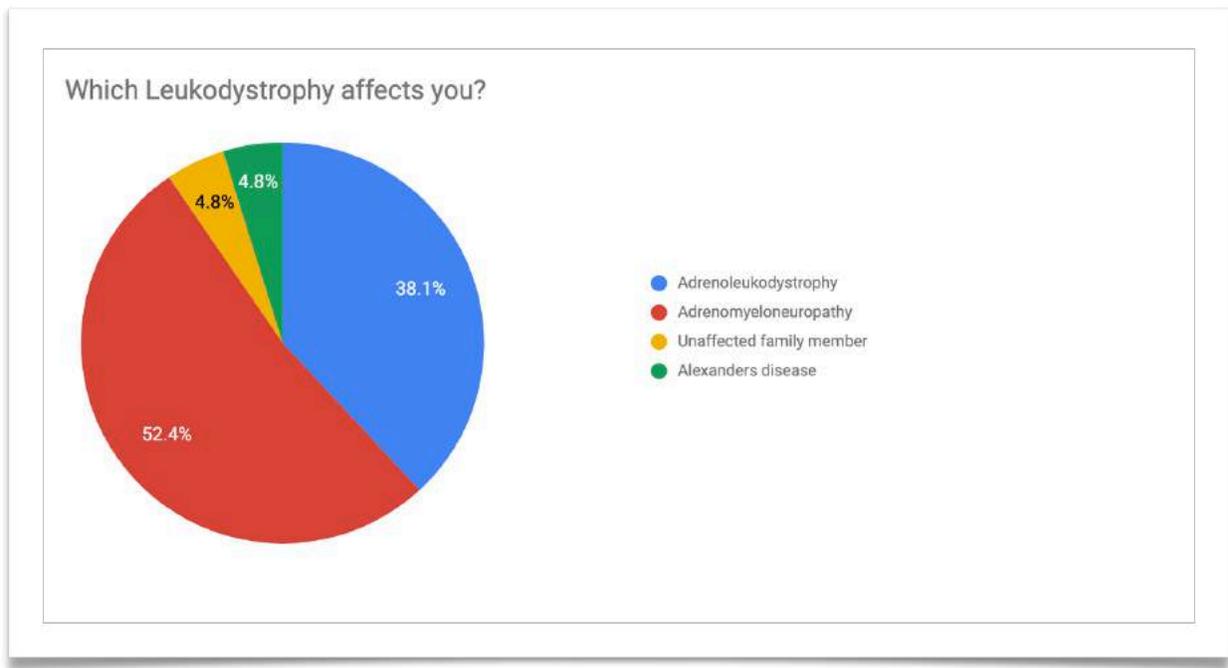
This is generally a similar profile to 2018 for groups of 2 or more, however, 2018 saw 32% of its survey respondents attend by themselves (groups of 1) whereas this represented just 6.7% in 2020. This is likely due to the online nature of the 2020 event making it easier for friends or family members to dip in and out of the sessions as desired or relevant, rather than having to travel to and commit to attending in person.

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Conditions represented

Respondents were also asked which leukodystrophy affects them and from a list of 50 + conditions. It was a multiple choice question and the majority of respondents selected more than one option, although all selected just 4 of the list of 50.

As you can see from the chart below, **Adrenomyeloneuropathy** was the most common selected condition with 52%, **Adrenoleukodystrophy** was next with 31%, **Alexanders disease** was the 3rd most popular with just 4.8% and another 4.8% reported that they were unaffected family members.



Alex TLC has only recently expanded its scope/ reach to include all Leukodystrophies which is likely why only 4 options were represented by survey respondents.

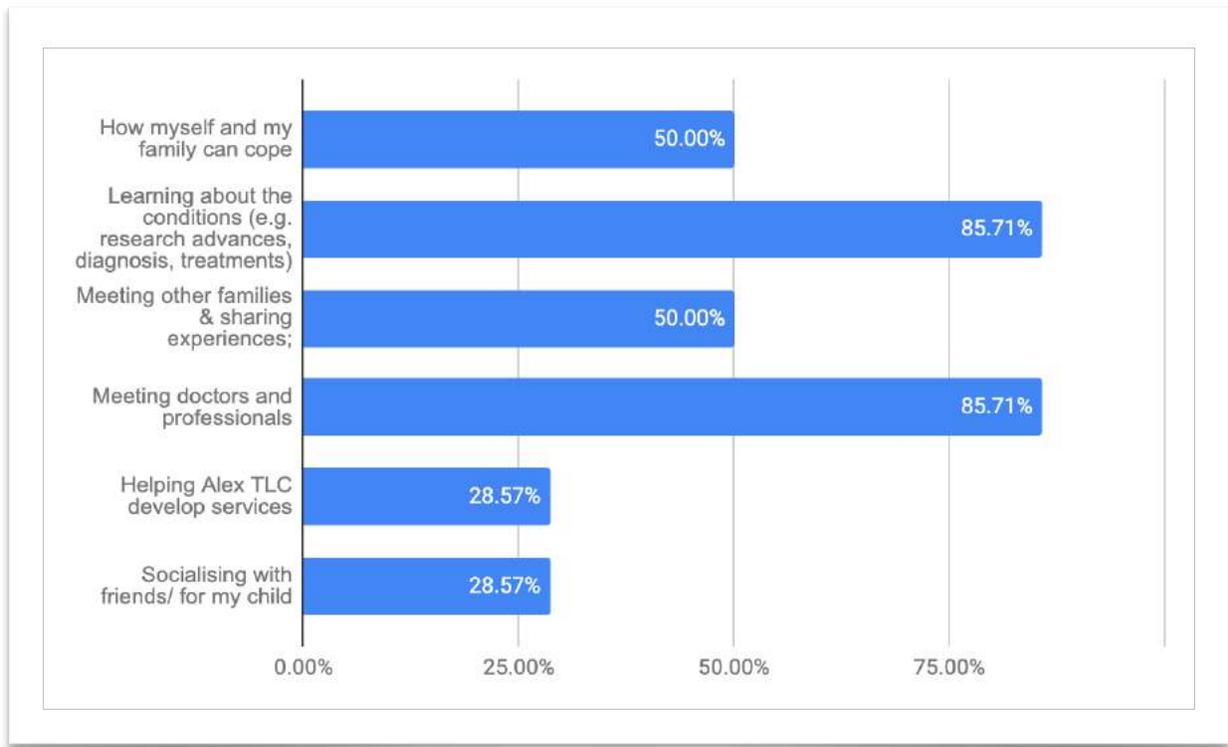
Although the agenda including sessions relevant to all the conditions, individual sessions specific to the conditions above may account for this. Additionally we are aware of attendees with other conditions who did not complete the survey. Activities to increase awareness of our expanded remit are part of ongoing strategy.

Event Feedback

Additional reasons for attending the event

In addition to their primary purpose for attending the event, we asked attendees what other reasons they had for attending. It was a multiple choice question and most survey respondents selected more than one option.

As shown in the chart below, 85.71% of survey respondents selected that they were attending the event to **learn more about the conditions** and **meet doctors and professionals**. The next most popular reasons with 50% of survey respondents attending the event, were to **learn more about how myself and my family can cope with leukodystrophy** and **meet other families with leukodystrophy and sharing experiences**. Finally, 28.6% of survey respondents confirmed they were attending to **socialise with friends/ enabling my child to socialise with friends** and **help Alex TLC develop their services**.



As the event in 2020 was the first time that Alex TLC sought feedback to develop their services at this event, it is understandable why this option did not receive many votes. Being the first online

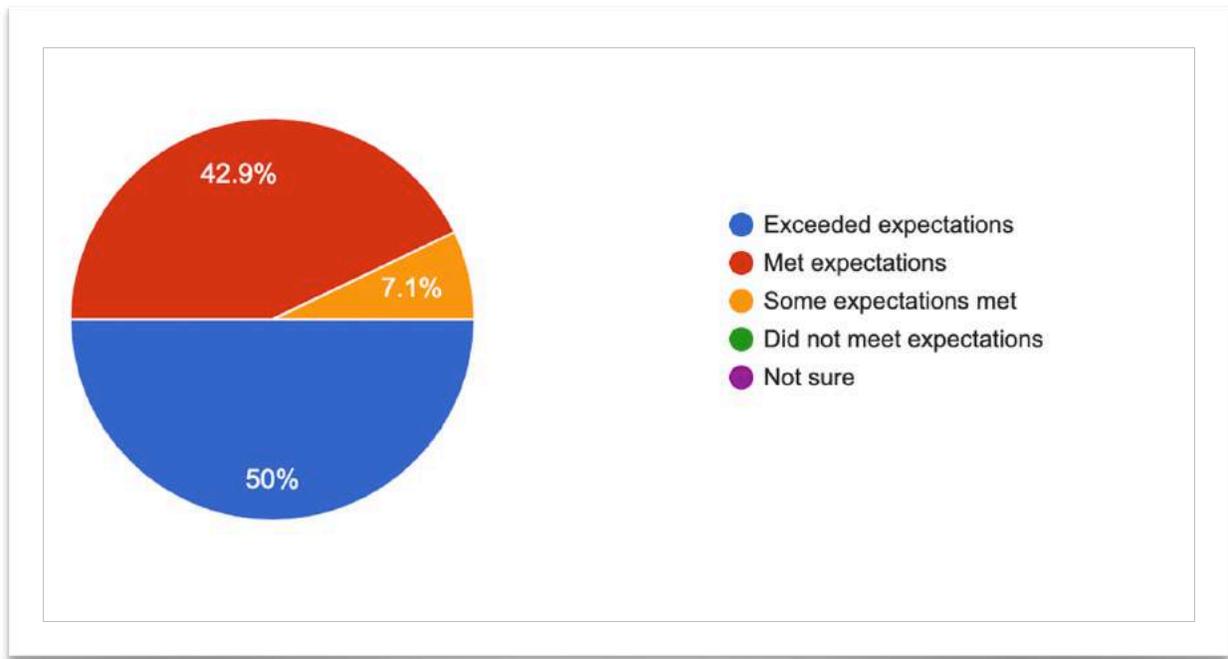
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event (forced due to the pandemic) it is also understandable why socialisation was less popular as a reason to attend this particular (online) event.

Apart from seeking feedback for services, the results in 2020 have a similar profile in terms of popularity to survey respondents in 2018 for whom the main reasons for attending were (in order of popularity); to learn about the conditions; meet the doctors; learn about how their families can cope with the condition; then socialise or enable children to socialise. A key difference however is that a larger number of people selected socialising as a key reason in 2018 with 67% selecting this option making it a very popular/ valued reason to attend. This will be due to the digital nature of the 2020 event.

Were expectations met?

All of this group had expectations met by the event with 50% confirming the event exceeded expectations.



Of the 7.1% reporting that “some expectations were met”, they did not provide any additional comments or clarification to this specific question. However, later in the report the same survey respondents reported that they struggled with technology and prefer face to face, which is likely to be the reason they selected “some expectations were met”.

The comments for this question were very positive and complimentary:

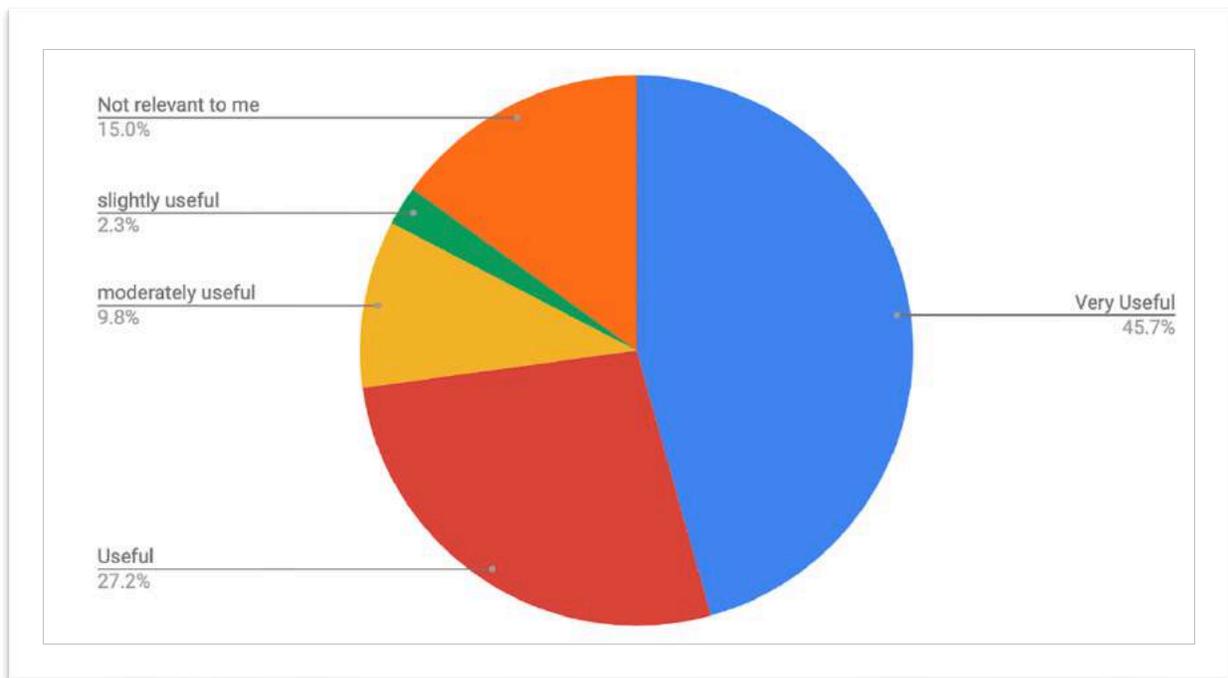
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- *“Thank you to Karen, Sara and all presenters - everyone clear and concise.”*
- *“Meeting and talking to others was going to be difficult on line. But the presentations worked very well, also the q and a. Well done”*
- *“It was very good to chat to fellow AMN sufferers and to some professionals esp. Dr Robin Lachmann. A real meeting would be very good when possible in future.”*
- *“Thank you for an amazing weekend.”*
- *“Speakers I attended were engaging and interesting and inspiring (Dr Collins call to arms for NBS!!!)*
- *“Karen Harrison’s management of the conference ‘flow’, and introduction of all the speakers was exceptional. She ‘linked in’, questioned and spoke with each speaker in a friendly and professional way. She made the conference a pleasure to follow. Thank you Karen.”*
- *“It was wonderful to be able to speak to Doctors who have knowledge of ALD, where so many local to us do not.”*

Presentation feedback

There were a total of 22 presentations over 2 days (please refer to the appendix for the full agenda). The attendees were asked how useful they found each of the presentations and for those who attended, the majority were rated very useful (45.7%) or useful (27%). No one selected the lowest rating of “not useful” for any of the presentations.

This chart represents the cumulative ratings for presentations across the 2 days:



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Comments were mostly positive and feedback generally referred to clashes with a desire to attend more of the sessions.

- “Range of topics was excellent”
- “I will listen to MIN 102 presentation online but it clashed with female AMN event”
- “I wish I had joined more sessions, the childrens activity sessions overlapped some sessions”
- “All relevant topics are covered”

It is worth noting that the majority of presentations were delivered in the main zoom ‘room’ whereas workshops and networking sessions were delivered in other rooms (with separate zoom links). This meant that *all workshops* clashed or overlapped with a presentation or Q&A session with the Doctors. Given the option, participants generally chose to attend the presentations with updates from Doctors rather than workshops. As evidence of this, many participants commented that they would have liked to attend the breath workshop on the Saturday morning, but could not miss the adult bone marrow presentation with Dr Wolfgang Köhler, running at the same time. It is therefore recommended to consider either running some of the workshops twice or designing the agenda for each key audience group (e.g. symptomatic men, female carriers etc) that allows them a balance of presentations and workshops without clashes.

The most popular presentations

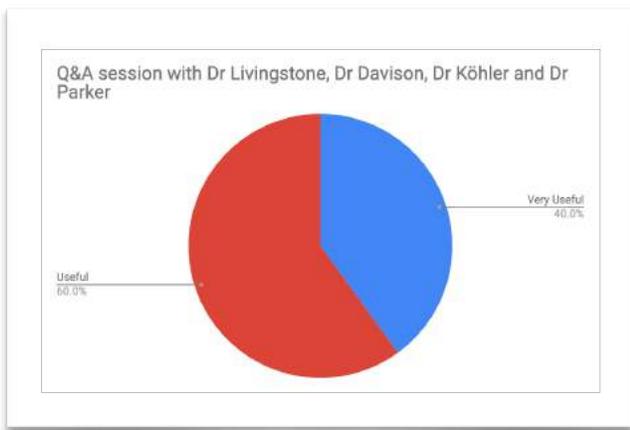
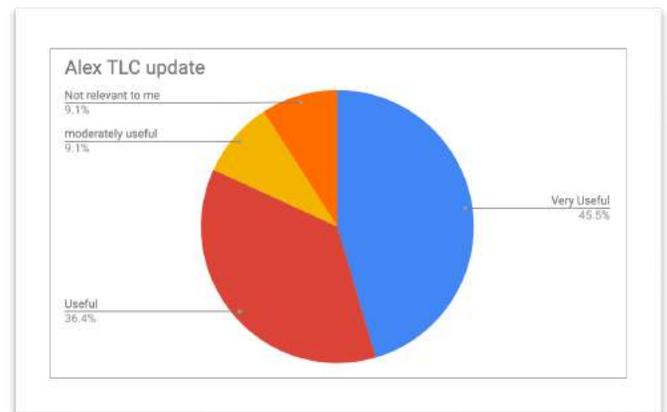
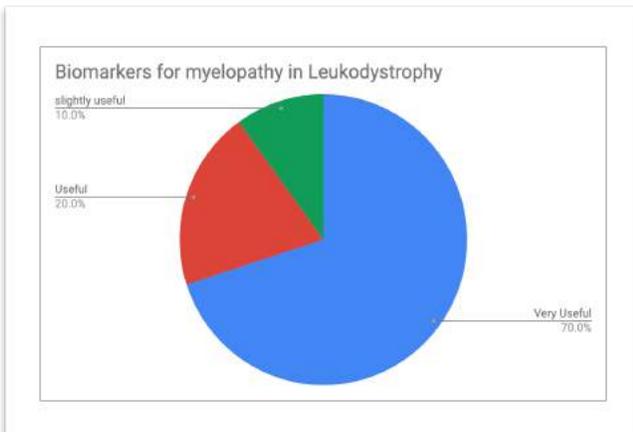
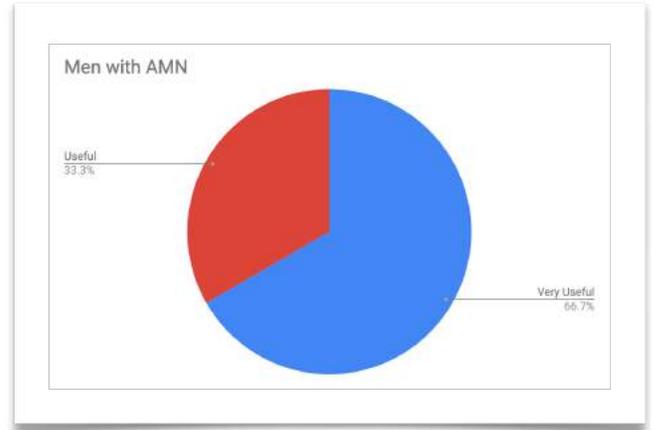
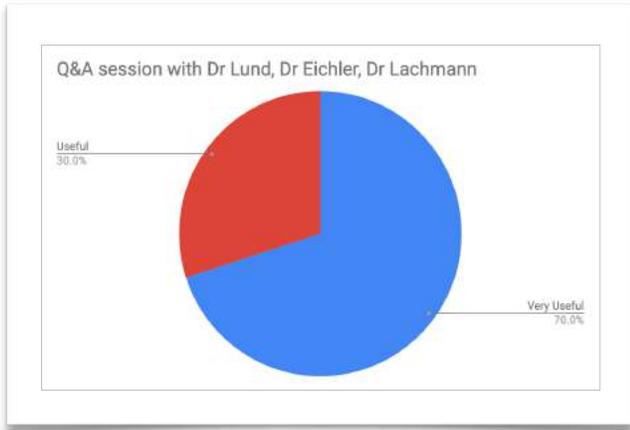


Using an average score of those who attended the presentation (i.e. removing those who selected “did not attend”), the highest rated sessions were as follows:

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- Q&A Sessions and presentations from Dr Livingstone, Dr Davison, Dr Köhler and Dr Parker
- Men with AMN
- Biomarkers for myelopathy in Leukodystrophy
- Alex TLC update

As you can see from the individual ratings for each of these sessions, the majority of those who attended found them to be useful or very useful;



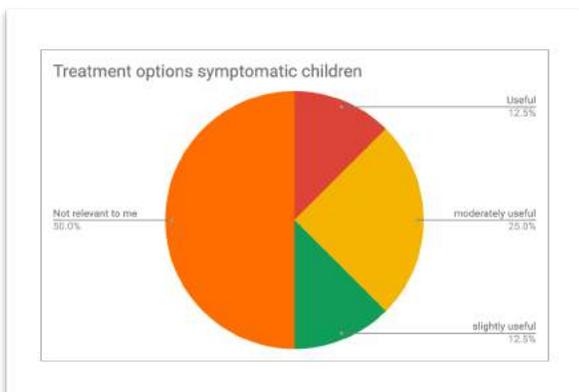
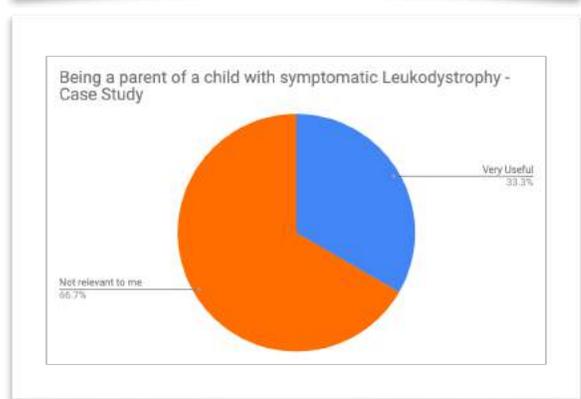
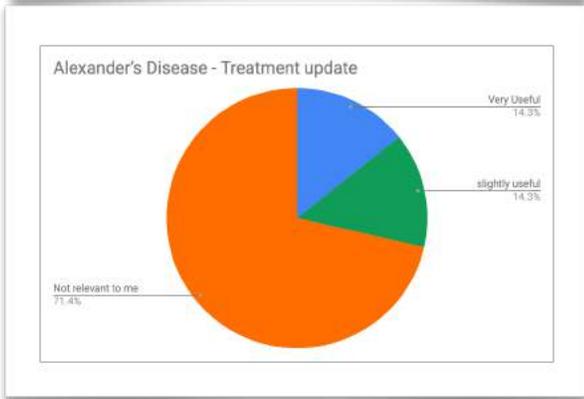
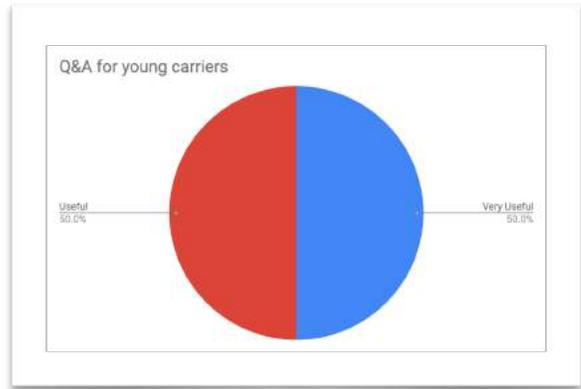
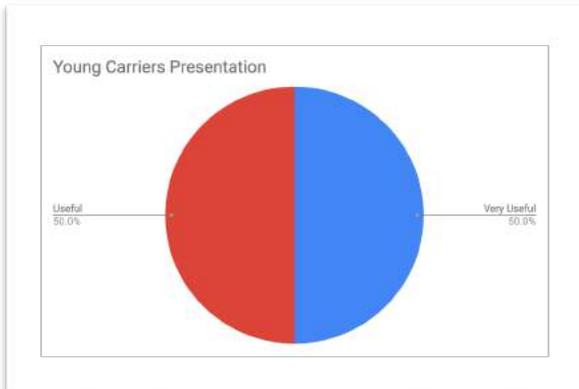
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The lowest rated presentations

Using an average score of those who attended (i.e. removing those who selected “did not attend”, the lowest rated sessions were as follows:

- Young Carriers Presentation
- Q&A for young carriers
- Alexander’s Disease - Treatment update
- Being a parent of a child with symptomatic Leukodystrophy - Case Study
- Treatment options symptomatic children

As you can see from the individual ratings charts below, many received ratings of useful or not useful and none received ratings of “not useful”. There were however, more people rating these as “not relevant to me” which brought their overall and average scores down.



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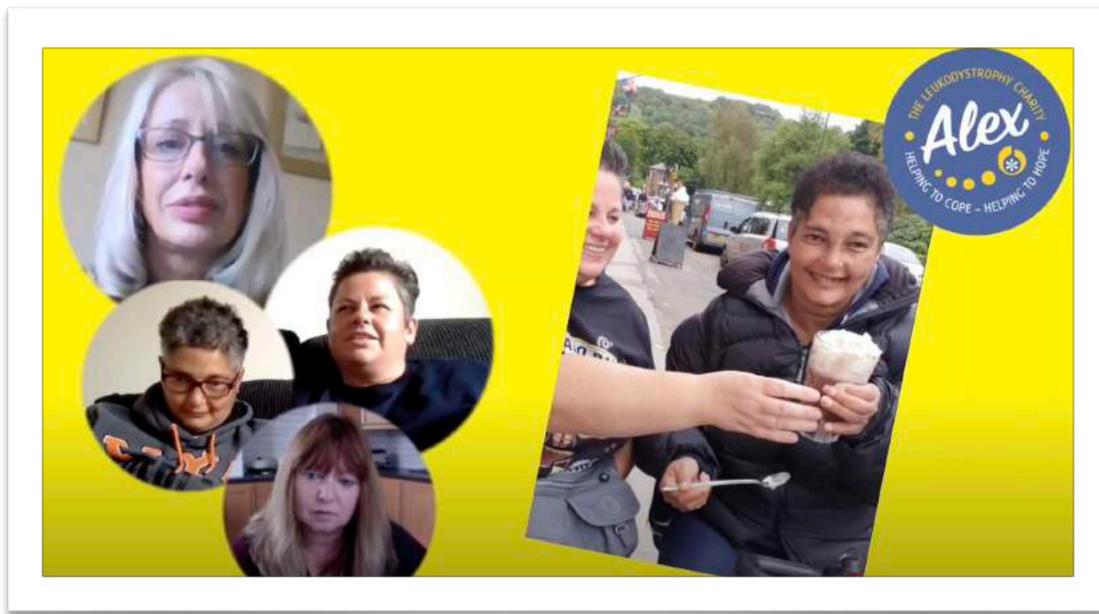
Whilst these were cumulatively the lowest rated presentations, it is worth noting that these were all very specialist sessions that were only relevant to a small population and none were considered “not useful” by attendees showing that they were still relevant despite receiving the lowest cumulative score.

When asked for feedback on those presentations that were less useful, survey respondents gave the following answers:

- *“I wish I had joined more sessions, the childrens activity sessions overlapped some sessions”*
- *“I did not like the way the [presenter] said that there was a drug regime to treat advanced cerebral ALD, but he would leave that to ALD Connect. He could have at least mentioned a few sentences about it as an introduction, stating a fuller presentation would be given on Friday 13 November. His presentation was, otherwise, first class.”*
- *“I will listen to MIN 102 presentation online but it clashed with female AMN event”*

When asked if there were any other topics they would like included, survey respondents gave the following feedback;

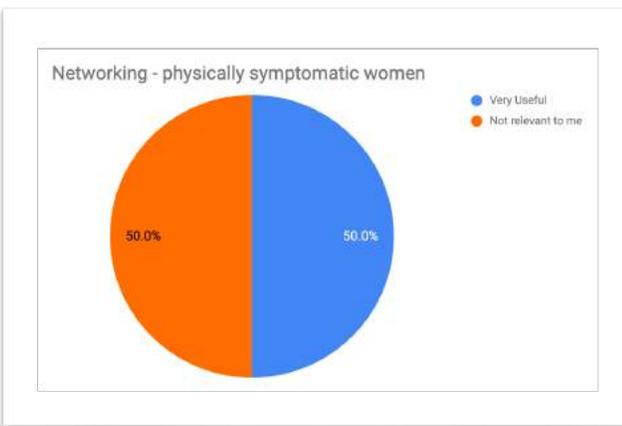
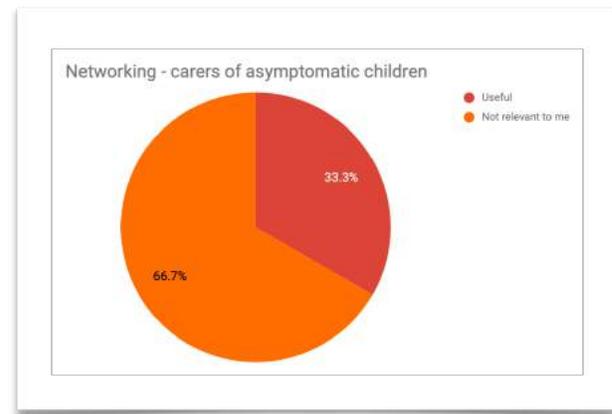
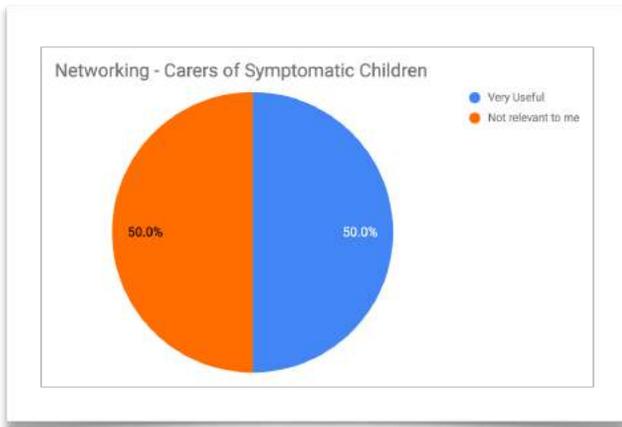
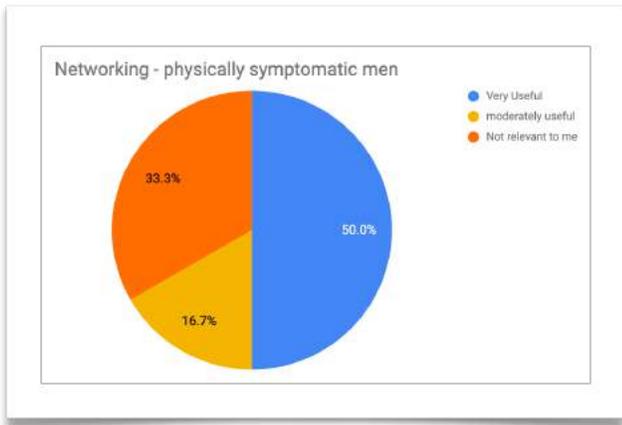
- *“Maybe on equipment, adaptations, physio? Preparing for the future”*
- *“CRISPR treatment for ALD and AMN”*
- *“All relevant topics are covered”*
- *“Range of topics was excellent”*



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Workshops and networking activities

There were 8 workshops and networking sessions offered in total, 5 of which were rated by survey respondents (note that different numbers attended or rated each workshop), as shown below. Note that *no one* selected “slightly useful” or “not useful” for any of the workshops or networking, showing that for those who did attend, ratings were all above a basic level of usefulness.



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You can see from the above charts that whilst the majority of survey respondents reported that the networking sessions and workshops were very useful or useful, there were some who recorded the sessions as “not relevant”. Having looked into the data, we can see that several survey respondents who recorded that sessions were “not relevant to me” did not actually attend that session and therefore selected this option in error.

It is therefore recommended that the survey question could be better worded (as “attended but not relevant to me” + “did not attend”) so we can differentiate between people attending in error (which could be down to poorly advertised or described sessions) and non attendance.

It’s worth noting that *all* of the workshops and networking sessions were offered at the same time as a presentation or Q&A session (with the specialist doctors) in the main room. This could account for the low numbers for these sessions.

Reasons for non attendance were not specifically asked for however, the following additional comment was captured later in the survey:

“Did you have any difficulties with these sessions, or do you have suggestions to improve them?”

- *“The 12pm session on Sunday - Men with AMN seems to have started sooner than planned so missed some of it. Similarly the following session started 7-8 mins early. I would have loved to attend the Breath workshop but it coincided with the unmissable Adult BMT talk”*

Additional comments/ were not requested directly after the workshops and networking review section in the survey, but after the childrens and family section which may have resulted in specific feedback and reasons for non attendance to the networking and workshops being missed.

Childrens and family activities

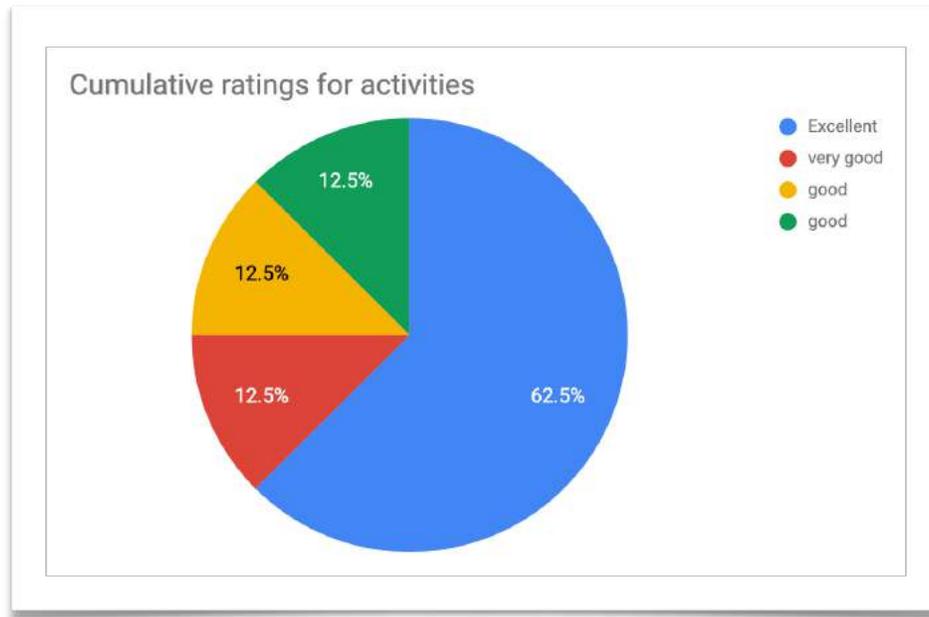
There were 3 children's activities and 3 family friendly sessions offered as follows:

- Creation station - a children and young persons creative activity session
- A Magic show
- A Children's literature development session
- A gameshow
- A quiz
- Max Pamph music session

We know from those who registered their interest and the numbers captured at the gameshow, magic show and kids creative, that there was between 43% and 64% drop off on the day for these sessions. This highlights the challenge of losing participants between sessions during an online event and the advantage of having a captive audience at in person events.

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Survey respondents confirmed they attended and rated 5 of the sessions and as you can see from the chart below, all rated the sessions as good, very good or excellent. No one rated the sessions OK, poor, or very poor.



In the comments, 9 responded that there were no children in their party which can be assumed as a reason for the low attendance at the activities from the survey respondents.

When asked if they had any difficulties with the sessions or suggestions to improve them, the following feedback was captured:

- *"The social side does not work so well online so hope we can get together next time"*
- *"Really well organised.. Lovely to end the weekend with a giggle."*
- *"I can't think of any improvements"*
- *"More about time constraints, lots of behaviours at home and being a full-time SEND Lecturer teaching young with LD, ASD and CB."*

In addition, general feedback on these activities was requested along with ideas for future activities:

- *"A digital conference has been a great success. Covid-19 has brought some benefits in this instance!"*

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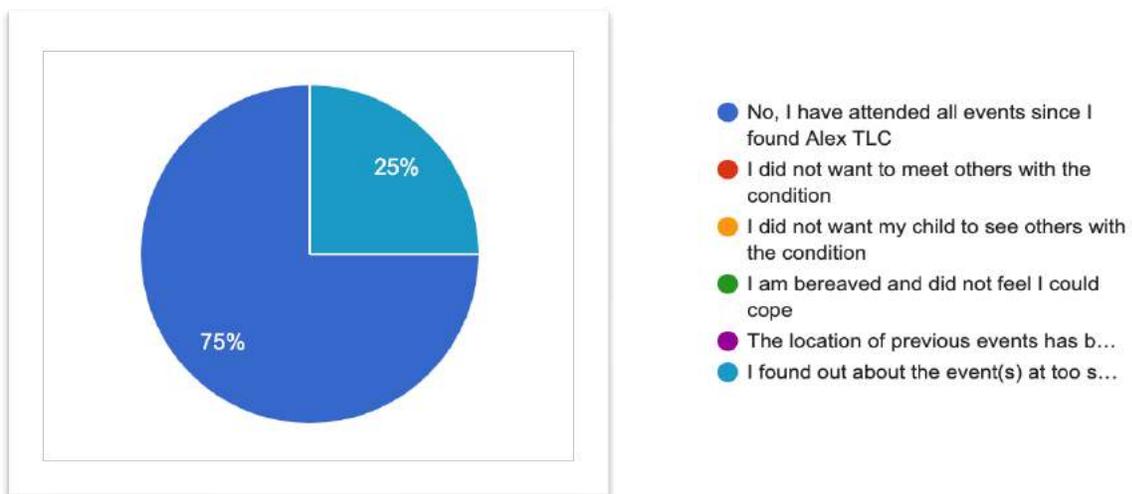
Familiarity with previous events

When asked if this was their first event, 71% of attendees confirmed that they had attended an Alex TLC event before, and 29% were attending their first event with the Charity.



When asked if anything "Has anything prevented you from attending an event in the past", 75% answered that they have attended all events since they found Alex TLC and 25% stated that they found out about the event at too short notice.

Comparison with previous events

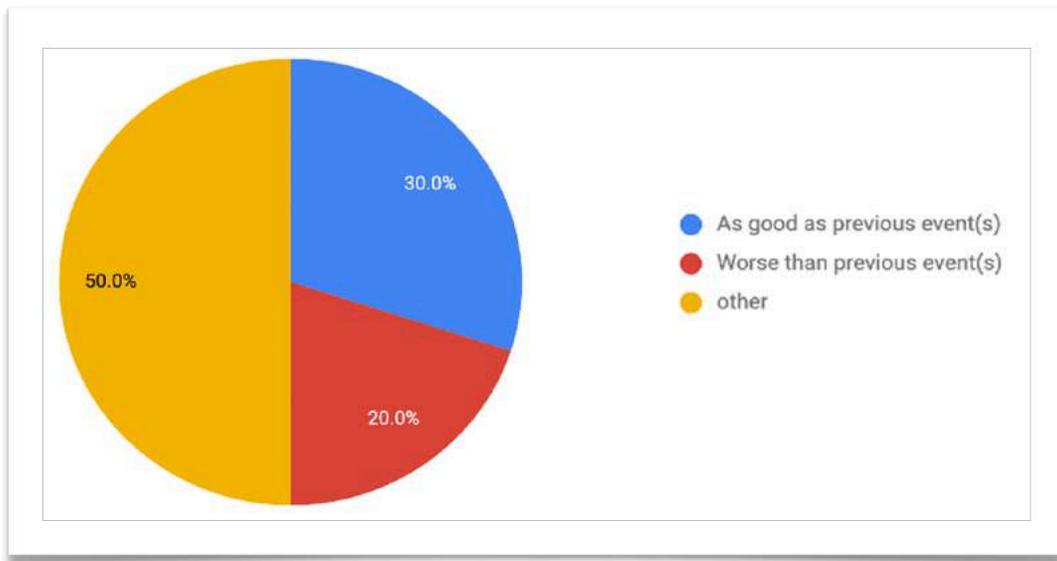


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When asked how this event compares to previous events, 30% of survey respondents confirmed the event was as good as previous events, 20% stated worse than and the remaining 50% who selected “other” reasons can be split into;

- 30% who **gave positive feedback** stating that the “*zoom event was first class*” and that it “*was good fun (but prefer meeting in person)*” and “*It’d be unfair to compare a ‘live’ event with a digital event. All I can say is that this one was a sterling event!*”
- The remaining 20% who were **neutral** or found it **hard to compare** giving the following reasons;
 - “*Hard to compare—I’m in a terrible time zone and being with everyone in in London is always the best. That said, I loved the look of the virtual setup and that the speakers showed up in a circle when they shared their screen. It’s the little things 🤔💙*”
 - “*Not worse just different but I do prefer face to face interaction which I understand is difficult at this time as I struggle with technology*”

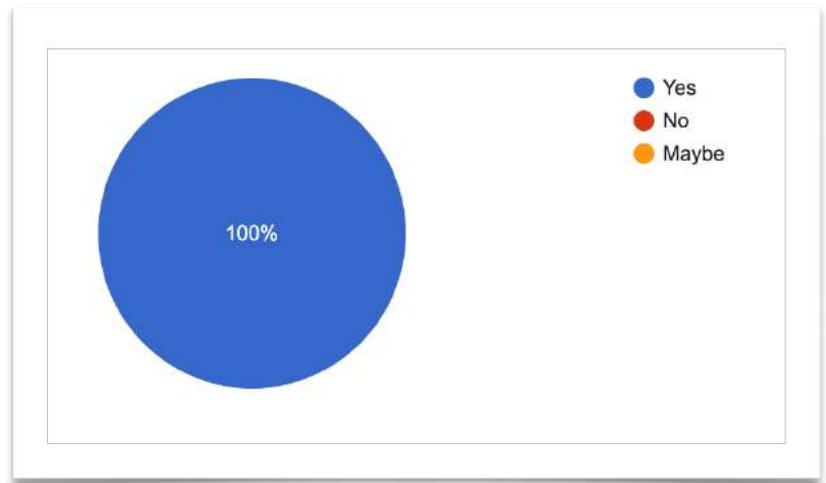
Overall this shows that people felt the event was better, however there is a clear preference for holding the event in person and recognition that it’s unfair to compare like for like.



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Would you consider attending an Alex TLC event in the future?

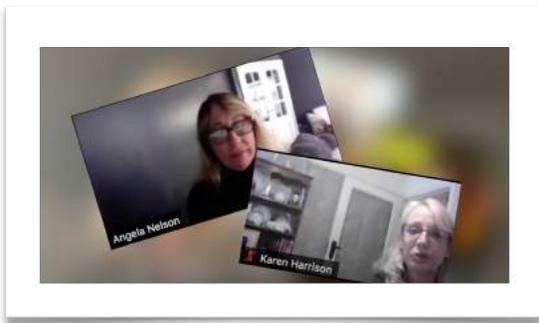
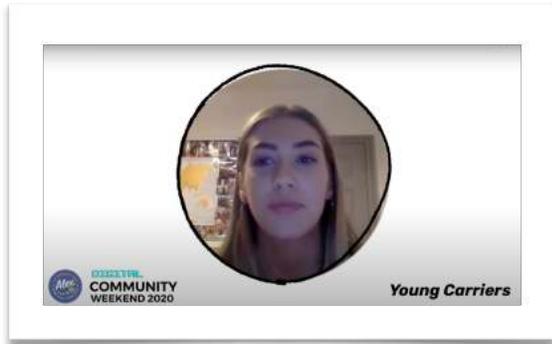
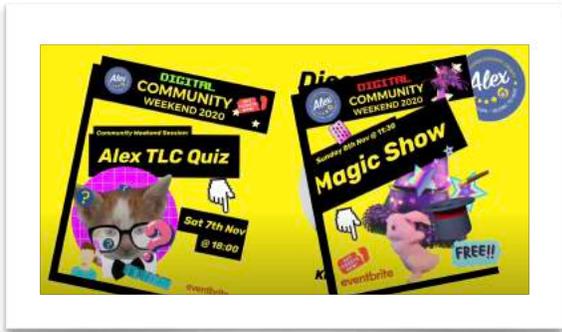
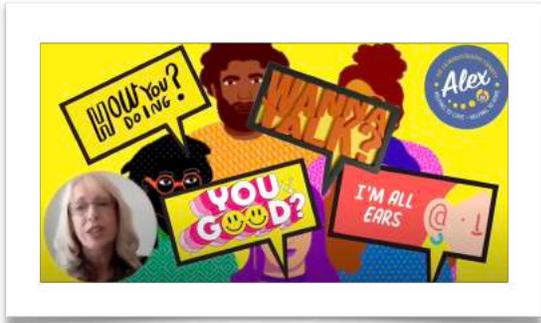
Despite the preference for face to face, it is positive to see that when asked if they would consider attending a digital Alex in the future, 100% of survey respondents answered yes.



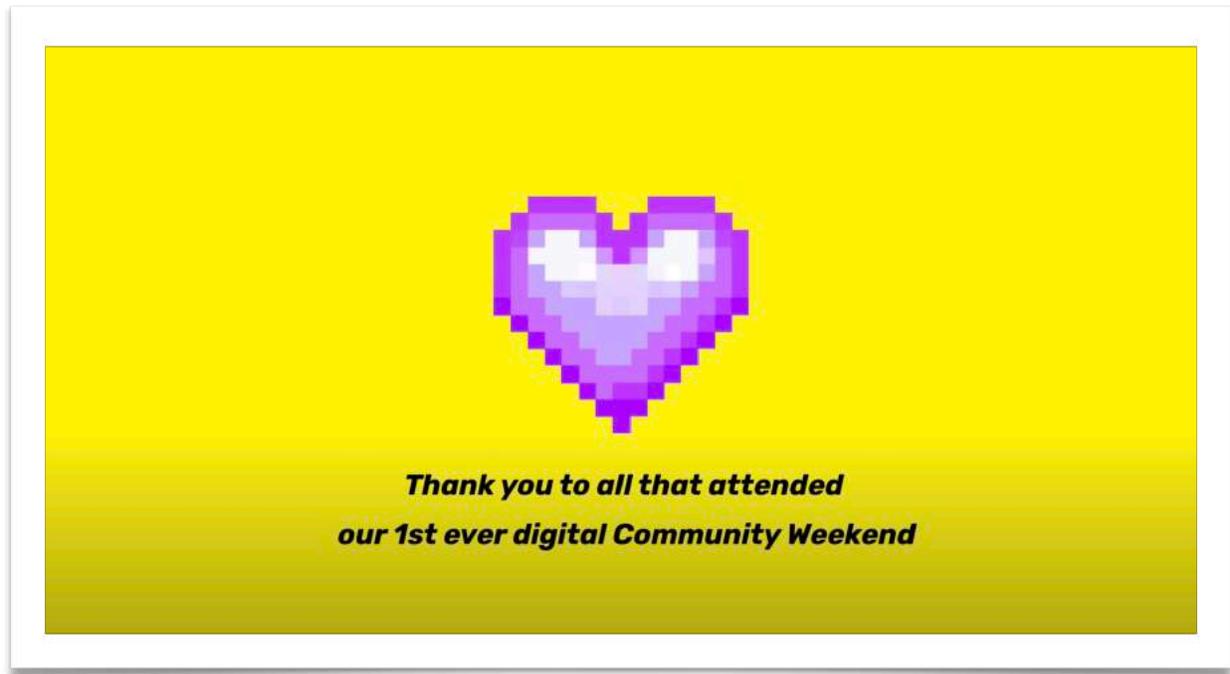
In support of this answer, survey respondents gave the following additional comments:

- *“This digital approach has been just as good as ‘the real thing’. Well done Alex TLC, and thank you.”*
- *“Obviously meeting in person at a venue is preferable, for being able to socialise etc, but in the circumstances it worked brilliantly. Possibly for some of the professionals from other countries it might always be better like this, but they too no doubt like having face to face contact with colleagues too.”*
- *“It has several positives, especially for disabled people as one can access the presentations from the comfort of own home”*
- *“I thought the presentations and Q&A sessions worked well digitally but the social side was not as good”*
- *“Anything is better than nothing.”*
- *“If it was the only option, digital is fine but you can't beat a true face to face weekend”*
- *“I would attend but hope for a real get together in future.”*
- *“I was surprised that there were not more AxD families attending, perhaps a separate group or talks may encourage more families to take part and meet each other?”*
- *“The professionals came over really well in digital fashion. It's true, you miss the company of other beneficiaries, but I'm fortunate enough to have attended two conferences in person, and I have met many people in the ALD community already. Yes - it is nice to meet up - but this digital conference met our needs in the circumstances. Thank you Sara, Karen and all who put the conference together. I thought the cheerful, colourful, modern background to each presentation was first class. Really brilliant 'Zoom' work - great IT people. Very professional.”*
- *“I struggle with technology”*

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In Summary



The majority of the feedback is positive, other than one individual who struggled with technology and a few comments highlighting a general desire to meet in person (which was not possible during global pandemic). There were also some considered and valuable suggestions for improvement.

One of our key learnings was not to hold so many concurrent presentations and workshops. It would also be advisable to plan the agenda for specific groups (organised by similar interest: i.e. carriers or symptomatic men etc) who can flow through the same sessions together allowing for a mix of presentations, workshop or activity and networking. The shared interested journey through relevant sessions will likely increase chances of participants feeling more familiar and at ease with each other and therefore increase chances of more attending the networking sessions.

By organising the agenda for similar interest groups, this will also aid the marketing and messaging before the event to promote certain sessions and increase numbers.

It may also be beneficial to run some of the workshops twice to allow everyone to attend.

“Not relevant to me”: In some instances, survey respondents selected “not relevant to me” for sessions they did not attend. This identifies an enhancement of the survey questions to differentiate between “attended but not relevant to me” (which suggests poor marketing/ inaccurate information

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provided about the session) verses “did not attend” (which may be because it was not relevant, but could also be because of a clash or unfavourable timing).

Whilst there are some presentations and workshops that can be delivered effectively remotely, it is clear that there is a strong desire and benefit to meet in person in order to both networking and provide critical and valued in person support for this community. The shared understanding of the challenges faced and opportunity to share stories and meet the doctors is invaluable.

Should an **online event of this nature be considered** again, it would be beneficial to provide a really clear supporter benefit for each session (or section of the agenda if grouped by interest).

It is also recommended that some technological set up and support, such as a short “how to use zoom” demo or workshop is provided to help users get connected and interact through whichever platform is used.

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Appendix A - Alex TLC Community Weekend 2020 Agenda

Day 1 - Saturday

Day	Time	Main Room	Room B	Room C	Time
Saturday	9:30	Alex TLC update Sara Hunt (CEO) and Karen Harrison (Support Services Manager)			9:30
Saturday	10:00	New NHS IWMD service and patient registry John Livingston, Professor of Paediatric Neurology, University of Leeds			10:00
Saturday	10:30	The importance of monitoring in children James Davison, Consultant in Paediatric Metabolic Medicine, Great Ormond Street Hospital			10:30
Saturday	11:00	BREAK	Optional Networking	Kid's activity - Creative Station * <i>Zoom links will be sent to registered participants the day before the event.</i>	11:00
Saturday	11:30	Adult Bone Marrow Transplant Update Dr Wolfgang Köhler, Universitätsklinik Leipzig	Breath workshop with Sophie Trew		11:30
Saturday	12:00	Treatment options symptomatic children Dr Alasdair Parker, Consultant in Paediatric Neurology, Addenbrooke's Hospital.	<i>approx 50mins introduction to breath meditation</i>		12:00
Saturday	12:30	Q&A session with Dr Livingstone, Dr Davison, Dr Köhler and Dr Parker			12:30
Saturday	13:00	LUNCH BREAK	Optional Networking		13:00

Day	Time	Main Room	Room B	Room C	Time
Saturday	14:00	Adult onset leukodystrophy Dr David Lynch, Specialist Registrar in Neurology at the National Hospital for Neurology & Neurosurgery	Young Carriers Presentation Taylor Kane and Olivia Bostock, patient advocates		14:00
Saturday	14:30	New born screening update Dr Stephan Kemp, Associate Professor, Amsterdam University Medical Centers Dr Jayne Spink, Chief Executive, Genetic Alliance	Young Carriers Q&A session Taylor Kane and Olivia Bostock, patient advocates	Carers of symptomatic children Networking session with Dr Alasdair Parker	14:30
Saturday	15:30	Biomarkers for myelopathy in leukodystrophy Dr Irene Huffnagel, Paediatric Neurologist, Amsterdam University Medical Centers	Carers of cognitively symptomatic adults - Networking	Children's literature interactive development session Moderator Ruth Dale <i>For Adults & children! Get involved with Alex TLC's project to help children understand a diagnosis.</i>	15:30
Saturday	16:00	Q&A session with Dr Lynch, Dr Kemp, Dr Spink and Dr Huffnagel		CLOSE	16:00
Saturday	17:00	BREAK	Optional Networking		17:00
Saturday	18:00	Alex TLC Quiz!	CLOSE		18:00
Saturday	19:00	MAX PAHMP MUSIC Music & open networking session			
Saturday	20:00	CLOSE			20:00

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Day 2 - Sunday

Day	Time	Main Room	Room B	Room C	Time
Sunday	14:00	Being a parent of a child with symptomatic Leukodystrophy - Case Study by Nahed Sarig, Alex TLC Trustee and Karen Harrison, Alex TLC	Physically symptomatic men Networking Moderator – Dr Robin Lachmann	Carers of asymptomatic children networking Moderator – Dr James Davison	14:00
Sunday	14:30	Case Study – Supporting Symptomatic adults Karen Harrison, Alex TLC			14:30
Sunday	15:00	Treatment update & Alex TLC Q&A session With Dr Lund, Dr Eichler, Dr Lachmann and Sara Hunt and Karen Harrison from Alex TLC			15:00
Sunday	16:00	BREAK	Optional Networking	Mindfulness session – live with Dr Pujit Gandhi	16:00
Sunday	17:00		CLOSE	CLOSE	17:00
Sunday	17:30	Game Show finale * Set up and networking starts at 5:30, games start at 6pm! <i>Zoom links will be sent to registered participants the day before the event.</i>			17:30
Sunday	20:00	CLOSE			20:00

Day	Time	Main Room	Room B	Room C	Time
Sunday	9:30	Alexander's Disease - Treatment update Dr Rahul Singh, Consultant Paediatric Neurologist, Guys & St Thomas' Hospital	Physically symptomatic women Presentation by Dr Elaine Murphy, Metabolic Consultant, National Hospital for Neurology and Neurosurgery		9:30
Sunday	10:00	Treatment update - MIN102 for ALD and AMN patients Minoryx Therapeutics.	Physically symptomatic women Networking	Resilience during Covid To help you unwind with Lou Robinson	10:00
Sunday	10:30	Q&A session on presentations and the work of Alex TLC with Minoryx staff, Dr Singh and Alex TLC staff			10:30
Sunday	11:00	BREAK	Optional Networking		11:00
Sunday	11:30	Predicting Cerebral disease remission after Bone Marrow Transplant Dr Troy Lund, Associate Professor, Department of Paediatrics, University of Minnesota	Roll up, roll up for the Magic show ! * <i>Zoom links will be sent to registered participants the day before the event.</i>		11:30
Sunday	12:00	Men with AMN Dr Robin Lachmann, Metabolic Consultant, National Hospital for Neurology and Neurosurgery			12:00
Sunday	12:30	Gene therapy Treatment update Dr Florian Eichler, Associate Professor of Neurology at Massachusetts General Hospital.			12:30
Sunday	13:00	LUNCH	Optional Networking		13:00