IMPACT REPORT

DIGITAL COMMUNITY WEEKEND 2021
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 impact, patient needs and developments in this area. Having previously been held in person, this year’s event was held online for the second year running 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 lunchtime networking, a mindfulness session and entertainment from Britain’s got Talent contestant Steve Royle. 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 20th and 21st November 2021. The 11th Community Weekend saw 2 full days of presentations, workshops and networking sessions and was the second year running and hosting an event of this size online.

There were initially 97 people booked to come to the event, of which 75 individuals and families with Leukodystrophy attended, plus 16 doctors, professionals and leukodystrophy workshop hosts. In addition there were 2 recreational session hosts (including mindfulness and a physical wellbeing activity) and a further 6 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 2020 Community Weekend Feedback Survey, in order to draw comparisons between responses to the two events, where possible or applicable.
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Of the 75 beneficiary attendees, 28% completed the survey. This 28% of survey responses represented 45 individuals and families affected by Leukodystrophy, which is equivalent to 46% of total attendees at the conference.

In terms of attendance there were 4% fewer people in 2021 than in 2020. This slight reduction is likely due to ongoing COVID-19 restrictions (and subsequent screen/zoom fatigue), as well as a lack of desire or ability for attending this type of event online.

However, as you can see from the chart below, there were 40% more survey respondents in 2021 than in 2020 and they represented 7% more of the individuals and families than in 2020.

Of those who did respond, comments were very complimentary of the event and it is also worth noting that whilst some survey respondents continue to prefer the face to face format, there is now a growing pocket of beneficiaries that prefer online in light of care needs and accessibility (see “reasons why a digital event is preferred” section below).

"Congratulations to you all. Incredibly professional meeting"
“Really great resource for families & professionals”

The survey asked 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;
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- 15% stated they would be happy,
- 38.5% said they might be and,
- 46% stated that they would not be interested in fundraising for the charity.

This equates to 53.9% who may be willing (Yes and maybe) to fundraise for the charity, compared to 71.5% in 2020.

As you can see from the charts below, this represents a 17% decrease in the numbers who may be willing to fundraise for the charity to the results of the 2020 survey (or an increase in those not willing to fundraise for the charity of 24%).

As well as one person stating “I am interested”, the following comments highlight beneficiaries other fundraising commitments and practicality of fundraising as reasons for not supporting the charity in this way, at this time:

- “Heavily committed to other fundraising”
- “Not practical at the moment”
- “All efforts going towards finding biomarker for my husband’s dx: Adult Polyglucosan Body Disease”

This decrease in appetite to fundraise for the charity by survey respondents could be related to a number of factors including;
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- The event was chargeable for the first time, with the patient and patient representative ticket price ranging between £5 and £15 (see “understanding reasons for charging” section for more detail).
- The number of fundraising “asks” around the same time as the event including the Big Give and Alex TLC raffle.
- The number of new beneficiaries attending the event for the first time, may be less familiar to the breadth of support and services provided by the charity (and therefore not yet ready to fundraise).

It is also worth noting that respondents were only presented with Yes, No and Maybe and the option of “Happy to contribute in many ways, but not fundraising” was not presented in 2021 as it was in 2020.

The question of fundraising from beneficiaries versus other means is being considered as part of our organisational fundraising strategy and we invested in a dedicated Fundraising Manager in October 2021.

This survey question is a starting point for further investigations.

**Recommendation**: It is recommended to re-introduce the “Happy to contribute in many ways, but not fundraising” option in future surveys, in order to capture those interested in supporting the charity in other ways. It is also recommended that the charity continues to explore the typical supporter journeys and engagement in terms of service use/ knowledge and fundraising appetite.

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.
DEMOPGRAPHICS

Age range

Many attendees joined the Digital Community Weekend with or on behalf of others, either having Leukodystrophy themselves or supporting family or loved ones with the condition. In the survey, we asked what the age brackets attendees and the people in their group or household fell into.

As you can see from the chart below, the most common age groups were **45 to 65 years** followed by **25 to 44 years old** with 37% and 29.6% (respectively) of people in those ages ranges. The remaining age ranges of **0 to 16 years**, **17 to 24 years** and **over 65's** shared a third (33.3%) of the remaining population with 11.1% each.

This is similar to 2020 in that the most common age group was 45 to 65 year olds with a small majority.

There is however a notable difference in the reduced representation (of survey respondents) amongst children and teenagers/ young adults; with 11% of 0-16 year olds in 2021, compared to 21% in 2020 and 8% of 17-24 year olds in 2121 compared to 14% in 2020.

With a similar % of over 65's (16% in 2021 and 18% in 2020) the increase is seen in 25 to 44 year olds with 30% in 2021 compared to 14% in 2020.
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Conditions represented

Respondents were also asked which leukodystrophy affects them 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 8 out of the list of 55.

That's 4 more conditions represented than in 2020 (4 out of 50).

As you can see from the chart below the most common condition impacting our survey respondents was Adrenomyeloneuropathy with 45%. Adrenoleukodystrophy and Unaffected family member were the next most common conditions both with 15%.

The remaining conditions that each represent 5% of all conditions affecting survey respondents (and were also new for 2021), were: Adult Onset Autosomal Dominant Leukodystrophy (ADLD), Aicardi-Goutieres Syndrome (AGS), Leukoencephalopathy with calcification and cysts (LCC), POLR3 related leukodystrophy and Polyglucosan Body Disease (PBD/APBD).

This shows a positive step towards Alex TLC supporting beneficiaries impacted with some of the rarer forms of leukodystrophies as we expand our remit.

This followed a similar profile to 2020 with Adrenomyeloneuropathy and Adrenoleukodystrophy being the most common conditions affecting our survey respondents with 52%, with 31% respectively. Interestingly Alexanders Disease was the 3rd condition selected by survey respondents in 2020, however, none of our 2021 survey respondents reported that they were impacted by Alexanders disease. This is not to say that no attendees were impacted, just survey respondents.
Recommendation: Recommend that there are more on the day opportunities to capture both type of Leukodystrophy and the symptoms they are impacted by/interested to learn more about throughout the event so that we can capture as many as possible that are represented at the event, without relying on survey completion. This could be done both publicly through chat/breakout rooms to encourage interaction and increase potential rapport building between attendees, as well as privately through chat and anonymous surveys to allow those more reserved or unwilling to share publicly.

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 that they were connected with Leukodystrophy.

As you can see from the chart below, the most common connection with leukodystrophy is **Symptomatic** with nearly 24%. This is followed by **Carrier** with 19% and then **Asymptomatic, Caring for Someone with Leukodystrophy** and **Unaffected Family Members** being the next most common with 14.3% each. Survey respondents who were **Successfully Treated** counted for 9.5% of connections and there was just 4.8% having **Lost a Child or Partner to Leukodystrophy**.

![Connection with Leukodystrophy Chart](chart-url)
This follows a similar distribution to 2020 with the top 5 reasons being the same (albeit in a different order) and Symptomatic and Carrier being in the top 3 connections with Leukodystrophy in both 2020 and 2021.

This aligns with our understanding that most beneficiaries engage with the charity when they are recently diagnosed or actively looking for treatments or condition management techniques.
Main reasons for attending

We asked attendees what their main reasons were for attending the event. This was a multiple choice question and most survey respondents selected more than one option.

As shown below the most common reasons for attending the event were to **learn more about the conditions** and to **hear more from Doctors** with 26.7% of total responses each. The next most popular reason for attending was **learning more about how attendees and their families can cope with leukodystrophy** with 20%, followed by **helping Alex TLC develop their services** with 13.3%.

The least popular were **meeting other families and sharing experiences** and **socialising with friends/ for my child** with 8.9% and 4.4% respectively. These are likely the least selected options due to it being an online event and not as conducive to mixing with others as it would be at an in person event.

It is reassuring that the top two reasons for attending map perfectly to the design of our 2021 agenda which focussed on Science led presentations on day one, followed by condition management focus on day two.

These results also match the profile of responses to those in 2020 for the most popular reasons for attending (to **learn more about the conditions** and **hear more from Doctors**), as well **learning more about how (attendees) can cope with leukodystrophy** being the next most popular and **socialising**
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with friends/ for my child being the least popular. However meeting other families and sharing experiences was less popular than in 2020, likely due to the increase of people attending an Alex TLC event for the first time (see “familiarity with previous events” later in this report) as well as the limitations an online event has for socialising activities.

Also, helping Alex TLC develop their services was more popular than in 2020.

Attendance on different days

For the first time in 2021, we designed the agenda so that we would focus on science backed presentations on day one, followed by condition management on day 2. As you can see from the chart below, day one was the most popular in terms of attendance with 92% of overall attendees joining for the science backed presentations.

Looking at attendance by session, we can also see that the most popular sessions were the Q&A sessions on Saturday, followed by Dr John Livingstone and the Minoryx update. And for Sunday, the most popular sessions were the Q&A session as well as the Alex TLC Support Services update and Expectations of patient care. Please see the full agenda in appendix A.
A full summary of the Q&A sessions was provided to all beneficiaries on our website following the event (linked here).

**Recommendation:** It is recommended that Alex TLC increases the time given for questions as well as live interaction with the Doctors and professionals and sets aside contingency or free time after the Q&A sessions that allow for over running in case required.

**Recommendation:** It is recommended that Alex TLC focuses future digital events on research as this attracted more interest.
EVENT FEEDBACK

The survey was split into two parts where those affected by a leukodystrophy and professionals were asked a slightly different set of questions. Those affected by a leukodystrophy made up 62% of survey respondents and we will look at their responses first.

Were expectations met?

As highlighted earlier, the top 3 most common reasons for attending the event were to **learn more about the conditions, hear more from Doctors and learning more about how (attendees) can cope with leukodystrophy.**

When asked, all of this group (those impacted by a leukodystrophy) confirmed that **the Alex TLC Community Weekend was useful for those with Leukodystrophy and their families.** And when prompted, no one gave any feedback as to how we can make the event more useful.

We also asked what impact the weekend had on their knowledge of the condition, condition management and connections with others and all respondents confirmed that their knowledge either stayed the same or improved across all three areas.

- 40% confirmed the event **improved their knowledge of their condition,**
- 40% confirmed the event helped **improve their condition management,** and
- 30% of respondents confirmed the event **improved their connection with others.**

The follow comments were given in support;

- “The weekend was brilliantly presented, and it helps our family keep in touch with any new drugs and companies coming to the fore to help treat AMN. Developments are slow, and Alex TLC lets us see the companies involved, and hear how they may succeed in bringing new drugs
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to the market”
● “Useful to reinforce existing knowledge and to learn about current research”
● “The work into development of IWMD services in NHS and information about this”
● “A range of topics increasing knowledge of the range of leucodystrophies”
● “It was very interesting to listen to some of the doctors, especially those that said there will be some help for us ladies having some medical assistance.”
● “It improved by getting professionals, suffers and their families together.”
● “The updates on drug research and on symptom management in AMN adults was very useful.”
● “Learning about new scientific developments is great.”

Presentation feedback

There were a total of 20 presentations over 2 days (please refer to appendix A for the full agenda & note that different numbers attended and rated each workshop).

In the survey, we asked attendees to rate the presentations across 5 themes:
- Condition Management,
- Research Updates,
- Alex TLC Services,
- NHSE IWMD Patient registry services and
- Newborn screening.

The following chart represents the cumulative ratings for presentations across the 2 days. For those who attended, the majority were rated useful (94.3%) with a small number rating some presentations as not useful (5.7%).
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When asked to give more context, the majority of survey respondents gave very positive feedback;

- “NHS England Patient registry was very good...particularly Dr Livingstone. Minoryx Therapeutics useful to hear about being extended to women. Rahul Singh new NHS registry was good. Support for symptomatic patients was good. Professional Q&A was good. A couple of presentations went in and out of focus on words and one was difficult to read as the writing was small.. I found Mark Martinell difficult to understand. Steve Royale was funny”
- “Very useful indeed, found them all very interesting.”
- “The topics were relevant to my needs”
- “They contained lots of information that I was not aware of and I can share this with our cohort.”
- “All useful. An amazing agenda.”

It’s worth noting that all the “not useful” ratings were given by the same survey respondent for Alex TLC services, Newborn Screening and NHSE IWMD Patient Registry and Service presentations. This individual commented that they were “always looking to find researchers who might collaborate w[ith] APBD researchers”. If this was their primary reason for attending sessions, it is easy to see why they didn’t find those particular sessions” useful”.

**Recommendation:** It is recommended to include ‘attended but not relevant to me’ in the survey to differentiate between “did not meet (advertised) expectation” (i.e. poor content) versus “not relevant”. Also recommended to give a range of positive versus negative ratings (i.e. met/ exceed expectations) in order to better measure popularity.

The most popular presentation types

The presentation types in order or popularity (i.e highest #survey respondents who rated each presentation category/ type as useful) were as follows:

- Condition Management
- Research Updates
- Alex TLC Services AND NHSE IWMD Patient registry services (joint 3rd)
- Newborn screening
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Professional feedback

All professional respondents reported that their knowledge about leukodystrophy research had improved, with 75% also reporting that their understanding of the impact leukodystrophy has for patients and carers had improved. 37.5% reported the event had improved their connections with other professionals, and 87.5% reported their understanding of Alex TLC’s work and services had improved. The remaining percentage all reported these factors had remained the same.

- Recent information, good presentations, diversity of themes
- Superb range of sessions, all given by experts and highly informative. Learned about new and emerging therapies, state-of-the-art in newborn screening internationally and the very wide range of services provided by Alex TLC
- Dr Wolf’s MLD talk where my practice is likely to change by being more proactive.
- Really great weekend, great speakers.
- ...the Q&A was really in-depth, with excellent clinicians giving detailed views on a range of topics

All respondents indicated they would be interested in attending another digital event, with 62% showing interest in an in person event also. Those that indicated interest in only a digital event reported these were easier to access with their workloads.

Feedback on individual presentations was that those that had been attended were all useful with comments:

- It was interesting to hear what projects Alex leukodystrophy have been involved in
- I thought that the balance and coverage of the whole meeting was as good as it is possible to get. A great achievement by everyone concerned.
- The ones I attended were very useful
- Very well organised
- Very considered answers from the panellists, giving a sense of a nationwide approach to care.

Newborn Screening Roundtable

As part of the community weekend, Alex TLC organised an international roundtable meeting to discuss the critical issue of early detection of adrenoleukodystrophy by newborn screening (NBS). This was held via zoom and attended by specialists from the UK, US, Germany and the Netherlands.

NBS is currently being performed in 23 US states and is expected to apply nationwide within several years; it is also being piloted in the Netherlands. Two applications by Alex TLC and expert
partners for this to be introduced in the UK have so far been declined by the UK National Screening Committee (NSC, 2017 and 2021) which is a cause of great sadness to Doctors, the Charity and the entire UK ALD community. Chaired by Professor Colin Steward, this roundtable sought the expertise and advice of the US, Dutch and other international professionals who have developed and are successfully implementing NBS for ALD to see how we could address the reservations raised by the NSC here in the UK.

“This meeting exemplified the pivotal role that Alex TLC play in bringing together the best international researchers and clinicians to advance knowledge, care and future therapy of leukodystrophies and efforts to convene such a meeting have been applauded by key Doctors in this field. A summary of what was learned at this meeting was shared with the attendees at the community weekend and the learnings made will have a major impact on the next application for NBS here in the UK.”  

Dr Colin Steward, Professor of Paediatric Stem Cell Transplantation from the University of Bristol
Workshops and activities

There were 6 types of workshops and activities offered in total, 4 of which were rated by survey respondents (note that different numbers attended or rated each workshop), as shown below.

Of those who attended, the majority (96%) of people rated the workshops and activities as useful.

Positive comments included:

- All presenters clearly know what they are dealing with, and are first class in their presentations.
- All were very useful indeed.

Of those who did not attend, the following comments were made:

- Unfortunately I couldn’t attend all the sessions
- I would have loved to attend the Accessible Disability sessions but was unable to
- I didn’t get a chance to attend.

This suggests that whilst attendance was low, there was still interest in the sessions and important to ensure that all ticket holders were able to access the recordings post event and Alex TLC continues to include breaks and avoid key session scheduling clashes.

The most popular workshops and activities

The workshops and activities in order or popularity (i.e. highest #survey respondents who attended rating as useful) were as follows:

1. Q&A Panels
2. Mindfulness session
3. Alex TLC “how to get involved”
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4. Accessible Physical Wellbeing activity

Entertainment

The weekend closed with entertainment with a live performance from Britain's Got Talent finalist, Steve Royal.

Of those who did attend the entertainment, 57% found it enjoyable, 14% found it “okay” whereas 29% found it not enjoyable.

“We had fun watching!”

Of those who did not attend, they provided the following context:

- “Other commitments”
- “The adult in our family has impaired vision, and his cognition is affected, and he cannot take part in the entertainment section.”
- “It had been a busy day”
- “I find those kind of event hard to connect with on zoom”
- “Time”
- “Conflicting priorities (sisters 40th birthday)”
- “Simply time commitments - I have a young family and weekend work is kept to a minimum”

Recommendation: It is recommended that entertainment is reserved for in person events and does not have the same impact for digital attendees.
Familiarity with previous events

When asked if this was their first event, 46.2% of survey respondents confirmed that they had attended an Alex TLC event before, and 53.8% were attending their first event with the Charity.

This shows a more balanced distribution of survey respondents joining for the first time versus attended in previous years. In 2020, 71% of survey respondents had attended an Alex TLC community event before and just 29% were new to this event.

When asked “Has anything prevented you from attending an event in the past”, 67% confirmed that they had not heard of Alex TLC before this event and the remaining 33% of survey respondents confirmed that they could not attend past events for personal reasons.
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Comparison with previous events

When asked how this event compared to previous events, 14% reported that it was better than previous events, 57% stated it was the same as previous events and 28.6% stated it was worse than previous events. We feel this indicated a preference for in person events.

Overall this shows that people felt the event was the same or better. When specifically asked if there was “anything we could have changed or done differently that would have improved our weekend?”, one person asked for more time for questions and remaining survey respondents were generally very positive:

- “No. I feel all items are included that concern families affected by cALD and AMN. Thank you all for your hard work, and excellent presentations."
- “It was as good as it could be [considering] it was on line”
- “It was a splendid event in these difficult Covid times”

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

When asked about their likelihood in attending a future Alex TLC event, the large majority (92%) confirmed that yes they would and overall, 76.9% of survey respondents would be happy joining either digitally or in person and 15.4% stated they would only consider digital. A further 7.7% of survey respondents stated they would “maybe” be interested and no one selected No. Interestingly, no one selected in person only - despite a preference indicated in previous surveys. It is likely those who prefer an in person event did not attend this year’s online event.
Reasons why a digital event is preferred?

We also asked if there were any reasons why survey respondents would prefer a digital rather than in-person event and the majority of survey respondents selected travel with 50%, followed by Care Needs and Costs, both receiving 25% of votes.

![Pie chart showing reasons for preferring digital events](chart.png)

Having previously assumed that the majority of beneficiaries would prefer an in person event, this year’s event has identified that there is a real need for online events for some beneficiaries as well as in person. Final comments support the need for both online and in person events:

- “Face to face much better when practical.”
- “Hopeful we can meet up in person for the next one. ”
- “great to have it digital”

**Recommendation**: It is recommended that we continue with annual digital events, and plan for an in person event for 2023 which should be centrally based to allow access from all areas of the UK.
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Understanding reasons for charging

We chose to test charging a small fee for beneficiary tickets for the event in 2021.

This was in response both to the negative financial impact that COVID restrictions had on the Charity as well as a notable proportion of no shows coupled with research that suggested people were more likely not to turn up for a free event (suggesting that people valued chargeable events more even if the fee is small).

We set the full final price at £15 but offered 2 levels of discount with "early bird" £5 and "saver" £10 tickets to encourage people to sign up earlier, allowing us to better plan an agenda around actual ticket holder numbers and preferences. We also invited anyone struggling financially/ with the fee to contact us as we would offer free tickets.

We outlined our reasons for charging in our marketing and ticket communications and also wanted to capture feedback in the survey.

When asked "We charged for this event because like many small charities we have seen a significant fall in income from reduced fundraising activities and voluntary donations. Did you understand the reason we charged for the event and think it was valid?"

All survey respondents answered ‘yes’.

Ticket sales earned the charity £530 net from ticket sales (£600 gross), compared to £288 (£305 gross) ticket sales (to pharmaceutical companies) and donation tickets in 2020.

**Recommendation:** It is recommended that we do not charge for future digital events.
FINAL THOUGHTS

We asked respondents for their final thoughts from our survey respondents, who took the opportunity to compliment and thank the charity for the event;

- “Keep up the good work”
- “Thank you for keeping us connected to developments in this terrible condition.”
- “Research updates excellent. Easy to join sessions and good to have an occasional break when sessions were not of interest.”
- “I think the weekend is amazing to increase knowledge and to support families.”
- “Thanks”
- “Thank you for being there.”
- “Thank you to Alex TLC for putting together an excellent weekend.”
- “Pre-recorded sessions was a great idea!”
- “This was an exceptionally well organised event, and I hope my small contribution brought some value to the community. Keep up the excellent work!”
- “this weekend has been really informative with engaging speakers and room for questions.”
IN SUMMARY

Having completed the second online event it is encouraging to see a wealth of positive comments and thanks from beneficiaries both during the event and through the survey questions and comments.

Whilst it was initially disappointing to have fewer beneficiaries reporting that they are willing to fundraise for the charity, it actually aligns with an understanding that the majority of beneficiaries engage with the charity to actively seeking support. If you couple that with the number of new beneficiaries attending this event for the first time, it could be considered that they are less likely to be warm to fundraising as they are at the beginning of their relationship with the charity and not fully aware of the breadth of support and work the charity does on behalf of those with leukodystrophy.

It is encouraging to see a growth in the number of beneficiaries attending the event for the first time as well as a number of new conditions being represented, including Adult Onset Autosomal Dominant Leukodystrophy (ADLD), Aicardi-Goutieres Syndrome (AGS), Leukoencephalopathy with calcification and cysts (LCC), POLR3 related leukodystrophy and Polyglucosan Body Disease (PBD/APBD). This shows a positive step towards Alex TLC supporting beneficiaries impacted with some of the rarer forms of leukodystrophies as we expand our remit.

This year’s event also saw an increase in new beneficiaries/first time attendees to the community weekend. Looking back at the survey data, we can see that none of these new attendees selected a condition they were impacted by.

**Recommendation:** It is recommended that the Charity follows up with those new attendees to understand their reasons for not selecting a condition, as well as what needs they have, their expectations for the event and how the charity can support them going forward.

Finally, this year’s survey respondents highlighted that there are a number of beneficiaries who need (or desire) further community weekend events to be delivered online due to their accessibility or care needs. This is likely a common need across certain beneficiaries so an online delivery of certain information should continue to be considered as part of Alex TLCs overall service provision.

**Recommendation:** It is recommended that Alex TLC continue to develop a holistic communication and events program that considers both online and in person formats to cater for all beneficiaries.
## Appendix A - Alex TLC Community Weekend 2020 Agenda

### Day 1 - Saturday (Science)

<table>
<thead>
<tr>
<th>Time</th>
<th>Main Room</th>
<th>Room B</th>
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<tbody>
<tr>
<td><strong>10:00</strong></td>
<td>Welcome &amp; Alex TLC Update</td>
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<tr>
<td>Sara Hunt (CEO) and Karen Harrison (Support Services Manager)</td>
<td></td>
<td>&lt;br&gt;Webinar ID: 874 4065 9903</td>
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<tr>
<td><strong>10:15</strong></td>
<td>NHS England Inherited White Matter Disorders Patient Registry</td>
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<tr>
<td>Dr John Livingstone</td>
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<td>&lt;br&gt;Webinar ID: 874 4065 9903</td>
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<tr>
<td><strong>10:45</strong></td>
<td>Leptin research update (Adrenoleukodystrophy and Adrenomyeloneuropathy)</td>
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<td>Minoryx Therapeutics</td>
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<td>&lt;br&gt;Webinar ID: 874 4065 9903</td>
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<td><strong>11:15</strong></td>
<td>PIL770 and PIL065 for adrenomyeloneuropathy AHN Research Update Panel</td>
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<td>&lt;br&gt;Webinar ID: 874 4065 9903</td>
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<tr>
<td><strong>11:30</strong></td>
<td>Metachromatic Leukodystrophy (MLD) Research Update</td>
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<td>Professor Nicole Wolf</td>
<td></td>
<td>&lt;br&gt;Webinar ID: 874 4065 9903</td>
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<td><strong>12:00</strong></td>
<td>LUNCH BREAK - MEET AND CHAT</td>
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## Day 2 - Sunday (Condition Management)

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<th>Room B</th>
<th>Time</th>
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<tr>
<td>10:00</td>
<td>Day 2 Welcome &amp; Overview&lt;br&gt;Karen Harrison (Support Services Manager)</td>
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<td>Webinar ID: 861 3239 1838 Link to join: <a href="https://us06web.zoom.us/u/86132391838">https://us06web.zoom.us/u/86132391838</a></td>
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<td>10:15</td>
<td>Alex TLC Support Services&lt;br&gt;Karen Harrison &amp; Suzanne Gosney (Beneficiary Engagement Officer)</td>
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<td>10:45</td>
<td>Expectations of patient care and impact of new NHS Inherited White Matter Disorder Service&lt;br&gt;Dr Rahul Singh</td>
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<td>11:30</td>
<td>Long Term Impact of Bone Marrow Transplant&lt;br&gt;Claire Turner and Dr Rachel Cox</td>
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<td>11:50</td>
<td>Support for severely symptomatic patients (children)&lt;br&gt;Dr Alanander Parker</td>
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<td>12:00</td>
<td>Accessible Physical Wellbeing Activity&lt;br&gt;The Disability Foundation&lt;br&gt;(You will need: small elastic band &amp; a pillow or back cushion)&lt;br&gt;Meeting ID: 817 9809 9481 Link to join: <a href="https://us06web.zoom.us/u/81798099481">https://us06web.zoom.us/u/81798099481</a></td>
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<td>LUNCH BREAK - MEET AND CHAT&lt;br&gt;Meeting ID: 885 3358 3294 Link to join: <a href="https://us06web.zoom.us/u/88533583294">https://us06web.zoom.us/u/88533583294</a></td>
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The charity relies on fundraising and donations. You can support us by donating now at: [https://www.justgiving.com/alexic](https://www.justgiving.com/alexic)

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<tr>
<td>13:00</td>
<td>Genetic Counselling and Informed Wider Family&lt;br&gt;Jon Wells&lt;br&gt;Webinar ID: 861 3239 1838 Link to join: <a href="https://us06web.zoom.us/u/86132391838">https://us06web.zoom.us/u/86132391838</a></td>
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<td>13:55</td>
<td>Bone Marrow Transplants and Gene Therapies&lt;br&gt;Orchard Therapeutics&lt;br&gt;Katie Snel&lt;br&gt;Webinar ID: 861 3239 1838 Link to join: <a href="https://us06web.zoom.us/u/86132391838">https://us06web.zoom.us/u/86132391838</a></td>
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<td>14:10</td>
<td>Cambridge Rare Disease Network&lt;br&gt;Webinar ID: 861 3239 1838 Link to join: <a href="https://us06web.zoom.us/u/86132391838">https://us06web.zoom.us/u/86132391838</a></td>
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<td>15:00</td>
<td>Managing Mental Health&lt;br&gt;Dr Pujit Gandhi&lt;br&gt;Webinar ID: 861 3239 1838 Link to join: <a href="https://us06web.zoom.us/u/86132391838">https://us06web.zoom.us/u/86132391838</a></td>
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<td>15:30</td>
<td>Professional and Patient Q&amp;A Panel&lt;br&gt;Webinar ID: 861 3239 1838 Link to join: <a href="https://us06web.zoom.us/u/86132391838">https://us06web.zoom.us/u/86132391838</a></td>
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<td>16:00</td>
<td>Ways to get involved with our work &amp; Raffia Drew&lt;br&gt;Marienne Graham, Suzanne Gosney&lt;br&gt;Meeting ID: 847 2490 0007 Link to join: <a href="https://us06web.zoom.us/u/84724900007">https://us06web.zoom.us/u/84724900007</a></td>
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<td>Britain’s Got Talent Live Performance&lt;br&gt;Steve Riley&lt;br&gt;Meeting ID: 847 2490 0007 Link to join: <a href="https://us06web.zoom.us/u/84724900007">https://us06web.zoom.us/u/84724900007</a></td>
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Thank you! We'd love your feedback, please complete our Community Weekend Feedback Survey: [https://forms.gle/lyi47i9vZT92g3i66](https://forms.gle/lyi47i9vZT92g3i66)