ALD Life
Community Weekend 2018
Feedback Survey Report
INTRODUCTION

The ALD Life Community Weekend brings together ALD and AMN sufferers and their families, alongside doctors, researchers and scientists from around the world to support each other and discuss how ALD and AMN affects them. It gives sufferers and their families the chance to talk freely about mutual issues and focuses on activities designed to put attendees at ease and encourage interaction, such as an ice-breaker quiz, children’s activities for all ages and abilities, workshops on condition management and self-help, research and treatment updates. 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 at the Crowne Plaza Docklands Hotel between 4–7th May 2018. It was the largest event of its kind run by ALD Life so far. The 9th Community Weekend saw 2 full days of presentations for the first time and was attended by more families and professionals than ever before.

Presentations made at the event are available with summaries on the ALD Life website, alongside photographs taken at the event by photographer Ann Bloom.

181 people attended the event, of which 115 were individuals and families with ALD or AMN, 41 were professionals and 25 were staff and Trustees.

“I find it an inspiration to meet so many people who approach their condition so positively”

“The weekend is a great event as it brings together families and professionals from all over the world to share information and support; peer support gained at the event is invaluable”

“I thought the whole weekend was excellent and commend you for all the hard work you put into it”

The weekend was made possible thanks to the generous contributions of our sponsors
METHODOLOGY

Following the event, attendees were sent a Feedback Survey to gather their views on the weekend. This survey was designed by the Monitoring and Evaluation Officer (Clare Dickson), in consultation with the Support Services Manager (Karen Harrison) and CEO (Sara Hunt). It was also influenced by the design of the ALD Life Community Weekend 2016 Feedback Survey, in order to draw comparisons between responses to the two events. Monitoring and Evaluation questions asked on the event Booking Form were used in the feedback survey to give an impression of the effect of the weekend on management of ALD and AMN.

53% of attendees completed the survey; the 44 responses received often covered family groups and so represented 96 people.

The majority of respondents were affected individuals and their families: 81 of these have their views represented in the survey either directly or through a member of their family group. This figure is 70% of those affected who attended.

These 44 responses demonstrate a 110% increase in responses, with 21 surveys completed after the Community Weekend 2016.

The survey asks respondents questions on demographics and their condition/connection to ALD or AMN, before asking for feedback on the venue, presentations and activities, as well as the event as a whole. Strongly positive results are common, alongside considered and valuable suggestions for improvement.

Respondents are also asked about their willingness to support future events through accommodation contributions or fundraising. Contributing to accommodation is supported by a large majority, with notable interest in fundraising as well.

Professionals answering the survey were presented with different questions to reflect their reasons for attending the weekend and to remove irrelevant questioning. This group was also highly positive on the value of the weekend.

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; those who did not agree to this will not have their comments featured in this report or used elsewhere. This number was 7% of the total (3 respondents).
DEMOGRAPHICS

As mentioned, the majority of responses received in this survey came from individuals and their families. As shown below, 71% of those answering the survey attended the conference in order to seek support for their condition or the condition of a loved one. 4% attended in order to seek support after losing a loved one.

The remaining 25% attended due to professional involvement with ALD, AMN or ALD Life; this includes medical professionals, pharmaceutical representatives, partner organisations, communications consultants, Trustees and ALD Life staff.

Attendees often came to the Community Weekend as part of a group, particularly those with ALD/AMN or those supporting others with the condition. 6 survey respondents attended the weekend with at least one under-16 year old.
Respondents were also asked about their own condition and gave a variety of responses as shown below. This question was directed at the respondent themselves, rather than about someone they care for, and shows that a wide variety of phenotypes are represented here.

There are some issues with this data, however, as indicated in this table. This suggests that some respondents have misread this question, answering for those they care for rather than just themselves.

<table>
<thead>
<tr>
<th>Phenotype</th>
<th>Number of people</th>
<th>Comments on validity of results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female carrier</td>
<td>18</td>
<td>This was the most common recorded diagnosis of respondents</td>
</tr>
<tr>
<td>Symptomatic ALD</td>
<td>6</td>
<td>3 of these also selected ‘Female carrier.’ Females with ALD do not suffer cerebral symptoms, only AMN. It can be assumed that these respondents are mothers of symptomatic boys; all 3 indicated that they care for someone with Symptomatic ALD.</td>
</tr>
<tr>
<td>Post-BMT</td>
<td>3</td>
<td>2 of these 3 also selected ‘Female carrier.’ Females with ALD do not have bone marrow transplants; both later indicated that they care for someone who is post-BMT.</td>
</tr>
<tr>
<td>Asymptomatic ALD</td>
<td>1</td>
<td>This respondent has also selected ‘Female carrier,’ which already indicates their Asymptomatic ALD. They may be referring to those they care for; they then indicate that they do care for someone with Asymptomatic ALD</td>
</tr>
<tr>
<td>AMN</td>
<td>13</td>
<td></td>
</tr>
<tr>
<td>Addison’s Disease</td>
<td>6</td>
<td></td>
</tr>
<tr>
<td>Lost a child/relative/partner to ALD/AMN</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Caring for someone with ALD/AMN</td>
<td>12</td>
<td></td>
</tr>
<tr>
<td>Professional</td>
<td>11</td>
<td></td>
</tr>
</tbody>
</table>

Respondents were also asked about the condition of those they care for with ALD/AMN. This showed some crossover, giving further weight to the idea that the previous question was often misunderstood.

<table>
<thead>
<tr>
<th>Phenotype</th>
<th>Number of people</th>
<th>Comments on validity of results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Asymptomatic ALD</td>
<td>3</td>
<td>Most also selected other symptoms; 1 selected only this option.</td>
</tr>
<tr>
<td>Symptomatic ALD</td>
<td>12</td>
<td></td>
</tr>
<tr>
<td>Post-BMT</td>
<td>10</td>
<td></td>
</tr>
<tr>
<td>AMN</td>
<td>8</td>
<td></td>
</tr>
<tr>
<td>Addison’s Disease</td>
<td>11</td>
<td></td>
</tr>
<tr>
<td>N/A- Do not care for someone with ALD/AMN</td>
<td>3</td>
<td>2 of these 3 attended the event for professional reasons. The 3rd had previously indicated that they are a parent, relative or carer of someone with ALD/AMN</td>
</tr>
</tbody>
</table>
ALD/AMN is a genetic condition, often affecting several members of the family group. This often causes difficulties in establishing each member’s symptoms through surveys such as this. It is clear, however, that a wide range of phenotypes of ALD and AMN were represented at the Community Weekend and by those responding to the survey.

Following this question, those claiming to have a Professional Involvement in ALD/AMN were asked a different set of questions to those seeking support for themselves or others.
"From the perspective of a professional, I thought that the pacing of activities was even better than when I attended previously." — Professional Attendee of ALD Life Community Weekend 2018

Those attending the Community Weekend due to a professional involvement in ALD or AMN were asked questions relating to the Professionals’ Roundtable events and to their overall opinion of the event. 9 professionals answered these questions.

When asked for the reasons behind their attendance, most selected multiple options. Almost 80% of respondents attended the Weekend to meet professionals and families as well as to learn more about the work of ALD Life.

The event met the expectations of all professionals who responded; exceeding the expectations of almost half of this group.
Professionals’ Round Table events were held as discussion spaces for professionals only. There were three of these events, covering:

- Care Pathways
- ALD Life Expansion Plans
- New Born Screening

Survey results do not distinguish between these three events and are instead intended to contribute to an overall picture of their value for professionals.

This data is limited, as 4 of the 9 professionals completing the survey did not participate in this activity; their “N/A” responses have been removed from the below chart. These meetings were highly specialised and would not have been open to all those with a broad “Professional” involvement in the weekend.

None of the professionals completing the survey deemed the Professionals’ Round Table event to be “Not Useful.” Results are varied, however, with answers of “Slightly Useful” or “Moderately Useful” showing a lack of enthusiasm.

Comments suggest that these opportunities to share knowledge between professionals were greatly appreciated, but there was often “no clear agenda...someone present to keep everyone “on track” would help.”

Most professionals completing the survey were attending the event for the first time, with just 2 having attended previously.

One of these two claimed the 2018 event to be Better than previous event(s), while the other called it “As good as previous event(s).”

The respondent who gave feedback at a previous event was unable to tell if their feedback had affected this year’s event. These responses will be combined with opinions of other attendees later in this report to give a more valuable bigger picture.
INDIVIDUALS AND FAMILIES WITH ALD/AMN

Those attending the Community Weekend due to their own condition or that of a loved one had a variety of reasons for attending the event.

Over 80% hoped to learn more about ALD/AMN or to meet knowledgeable doctors and professionals.

For most of this group, the Community Weekend 2018 exceeded their expectations; just 3% (1 person) did not have their expectations met. This person comments that they had hoped for further information on Female Carriers; a point which is raised by other respondents and should be considered when planning future events.

An attendee whose expectations were exceeded describes the event as “…a perfect balance of medical information, social activities and a wealth of knowledge from around the world in one place.”
72% of individuals and families completing the survey had either attended a previous event or were part of a group in which at least one person had done so. These respondents were asked how the event compared to those they had attended in the past.

54% believed that the 2018 event was better than previous event(s) they had attended; with 29% of these describing it as Much better.

None of these respondents thought that the event was worse than those they had attended in the past.

These previous attendees were then asked about feedback they left at previous events. The chart below shows that response to feedback was a factor in this belief that the 2018 Weekend was better than previous events for many people.

Responses have been split into 3 groups to ease interpretation of this information.

Those who were positive about the impact of their feedback (Group 1) generally saw this year’s event as Better or Much better than previous event(s).

The group who saw the most improvement and were most likely to describe this year’s event as Better or Much better than previous event(s) did not leave any feedback previously.

Although no respondents claimed that their feedback had not made a difference, none of those who were unsure of its impact (Group 2) thought this year’s event was Much better than previous event(s). Arguably, those who saw no difference after giving feedback may be unlikely to have completed another survey.
From comments, the most notable and appreciated change this year was the extension to 2 full days of presentations. This allowed attendees “...to assimilate information better. Also allowed more time for reflection, networking and Q&As.”

Many were keen to point out that praise for this year’s event was not at the expense of the 2016 Community Weekend:

“Although I feel this event surpassed the previous one, I thought the Tower Bridge event [2016] was excellent too.”

“I thought the ALD Weekend in 2016 was fantastic, this year’s event was as well!”
LOCATION AND VENUE

Feedback was collected from attendees on the location and venue. These questions were not asked of professionals in order to create a shorter survey for this group and to focus on the needs of those more likely to have accessibility issues or other special requirements.

While most of these categories received overwhelmingly positive responses, there were more mixed results for Meeting Rooms and Meals.

Those who were dissatisfied with the meals commented on the lack of choice, particularly in regard to dietary requirements. Many of those who expressed dissatisfaction did not leave any comments. A buffet style meal was chosen this year in response to comments from the 2016 event, although some comments suggest this made access more difficult for those with mobility difficulties.

The below graphs comparing responses to this question following the 2016 and 2018 Community Weekends suggest a decrease in satisfaction with meals following this change. In 2016, a total of 90% of respondents were satisfied or very satisfied with the meals available, compared to 77% in 2018.

This information must be considered in light of the very low participation rates in 2016; this 90% represents just 19 respondents, while 77% 2018 results is 27 responses.
The question on Meeting Rooms was not specifically asked in the 2016 survey, so a similar comparison cannot be made here.

Comments on meeting rooms mentioned wanting to be able to **look at the screen and speaker at the same time**; the speaker’s podium was positioned between two screens, with some distance between each.

Seating arrangements were changed this year in favour of **circular tables**. Comments suggest this was “great for meals [but] wasn’t ideal for presentations. A conference style chair arrangement (like in 2016) would have been better.”

Conversely, one respondent comments “the screens in the presentation suite were ideally positioned, and the round tables for attendees- rather than straight lines of chairs- were a great idea.”

This year’s event was held at the Crowne Plaza Hotel London Docklands. This venue has been used for a previous ALD Life Community Weekend event, although the 2016 event was held at the Grange Hotel Tower Bridge. The 2016 survey revealed that although many appreciated the convenience of a central London location, the lack of parking facilities was sometimes an issue.

This seems to have improved in 2018; 85% of respondents were Very satisfied or Satisfied with the location. 81% felt this way in 2016, although 10% described themselves as Very dissatisfied.

Other comments on the location and venue used for the 2018 event were very positive:

- “Hotel and staff were wonderful. Staff were attentive without being pushy”
- “It was good to have the extra day and time for presentations”
- “Volunteers were brilliant warm friendly and reassuring”
- “…easy to get to via public transport”
PRESENTATIONS

Presentations at the 2018 Community Weekend covered a wide range of topics in the hope of providing relevant and valuable expert information to attendees. As demonstrated in the Demographics section, attendees had a diverse range of phenotypes of ALD and AMN, so this required a broad range of topics from diverse specialists.

The below graphs show feedback responses for each of these presentations. For the sake of visibility, the speaker’s name is used as the title of each presentation in these charts. A full list of titles and summaries of each presentation are available here.

These results show that presentations were often Very Useful to survey respondents. It is not possible to make all presentations relevant to the wide range of phenotypes supported by ALD Life, shown in the fact that every presentation has had at least one ‘Not relevant to me’ response.

The most positive comments on these presentations proclaimed that “all presentations, which were relevant to me, were first class.” Another claimed that there are “no improvements required.”
Technical jargon was identified as an issue, with many asking for language in the future to be more “patient/lay-person friendly.”

Multiple presentations took place before the opportunity was given to ask questions, which some found caused them to “lose the moment,” instead of being able to question presenters immediately. Others, however, found this to be a useful format. The option to submit written questions, such as at the 2016 event, was not available this year and prevented those who did not want to address the whole room from asking their questions.

Respondents were also asked for suggestions for topics which they felt had been missed or insufficiently covered at this year’s event. Suggestions included:

- Physiotherapy for AMN
- Equipment relevant for AMN patients
- Benefit application advice
- FES (Functional Electrical Stimulation)
- Mental health impact on patients and carers
- More on management on AMN symptoms
- How to talk to GPs when requesting investigation for symptoms
- Positioning for disabled children in terms of seating wheelchairs etc.

‘Symptomatic females’ was by far the most common suggestion for stronger focus in the future. A coping workshop for affected females to discuss symptoms was suggested.

One respondent pointed out that “that is no reflection on [ALD Life Community Weekend], as there isn’t the research being done.” The high frequency of comments and feedback relating to female symptoms highlights that women who are carriers of or have symptoms of AMN still feel their issues are neglected. Some women disagreed with information from published research presented at the event.
An important element of the ALD Life Community Weekend is the ability to question and talk to medical professionals. Following each group of presentations, attendees were invited to ask questions to presenters, and to question all presenters in a large group session at the end of the weekend. Professionals were also available to talk to individuals and families throughout the weekend.

These charts show the value of these opportunities to those who attended the weekend.

9% of respondents did not see the Q&A sessions as relevant to them; this same 9% did not find the opportunity to meet doctors relevant either.

Over 50% found these opportunities to be Very Useful, with no respondents rating these as Not Useful. Considering that the opportunity to talk to experienced professionals was a key reason given for attendance, this is not surprising.

In response to comments at the 2016 event, recordings were made of all presentations at the 2018 weekend to help those unable to attend all sessions.

Although 66% of respondents expressed an interest in watching at least one recording, issues with video and audio quality meant that it was not possible to share these recordings. Presentation slides and summaries were made available on the website as an alternative.

This recording issue alongside comments highlighting problems with microphones, speakers and projection indicate a need for focus on technology at future events to prevent further issues.
Support sessions and workshops also took place at the Community Weekend 2018. These took place in smaller meeting rooms, with some happening concurrently, meaning that attendance at each was lower than at the presentations.

These sessions and opinions given of each are shown in these graphs, with ‘N/A- did not attend’ responses removed.

Of these four sessions, only ‘Transition to Adult Services’ received a rating of ‘Not Useful.’ The comment with this rating shows disappointment that the session was cancelled. This shows some confusion in communications; as the session did go ahead.

The Mindfulness workshop was the highest rated of the four, with one attendee commenting “the mindfulness workshop exceeded my expectations. I am glad I attended at the last minute.”

All sessions were highly rated, although it is in many cases unclear if respondents attended sessions which were not relevant to them. In some cases, it seems they did not attend for this reason, but chose not to select ‘N/A- did not attend.’ This may indicate that options were not properly understood; the ‘Not relevant to me’ option could be removed in future to assume that those attending a session believed it would be relevant. If it proved not to be relevant, they could select ‘Not Useful.’
EVENING ACTIVITIES

On each of the three evenings, social activities were held to encourage attendees to get to know one another and to add a fun element to the weekend.

These activities were generally highly rated, with many commenters jovially noting that the Quiz held on Friday night was too difficult.

Saturday night’s Casino and Scalextric activities were “good for the kids and being able to interact with them.”

Only the Bridge Building activity received one ‘Poor’ rating, with the attached comment “great fun” suggesting an error in completing the survey. Others called the bridge building “very enjoyable” and “my most memorable moment of the weekend.”
CHILDREN’S ACTIVITIES

10 of those who responded to the survey had a young person with them who participated in at least one of the Children’s Activities. These activities were:

- Trip to the O2
- Activity Room
- Keir Hardie Recreation Ground
- Swimming

These charts show the trip to the O2 as the most popular activity, as well as being the one with the highest turnout among survey respondents. 70% described the trip to the O2 as Excellent or Very Good.

Comments show some confusion in where children should be dropped off and initial organisation of activities. Volunteers and staff running activities are highly praised:

“My son was very nervous but was very well supported by the volunteers and really enjoyed himself”

“[Staff and volunteers] at all these activities made [them] a great success. They were tremendous and worked really hard.”
FUNDRAISING AND ACCOMMODATION

The ALD Life Community Weekend has significant financial implications for ALD Life. It is currently funded by specific grants, support and attendance fees from pharmaceutical companies, unrestricted donations and through contributions by attendees. A raffle held at the event further contributes to the fundraising effort.

To supplement this, respondents to the survey this year were asked if they would be willing to consider fundraising for or contributing to accommodation for future events. 71% were willing to contribute to accommodation costs in future events, with at least two of these respondents having done so this year.

Attendees are given the option to contribute to these costs when signing up for the event but do not often do so. These results suggest that further encouragement in this area would make a considerable difference to voluntary contributions.

Just 31% were willing to fundraise for the event, although others expressed a willingness to sponsor others in fundraising activities.

Fundraising requires commitment of time, organisation and a network of friends and family to donate. Many may feel unable to do this. Increased support with this by ALD Life may encourage some of these to fundraise; just 20% ruled out the possibility of fundraising in future.

Some individuals and families at our events struggle financially to support their loved ones and benefit greatly from being able to attend this event. Care needs to be taken to ensure that these people are not discouraged or prevented from attending this valuable event due to pressure to contribute.
OVERALL IMPRESSIONS

Most attendees of the ALD Life Community Weekend believed that it was a useful, valuable event. 100% of professionals claimed that it was useful for them and other professionals, with 89% also seeing it as useful for those with ALD/AMN and their families.

The remaining professional believed it could be more useful for families if issues with audio-visual technology and layout of presentation rooms were resolved. These are also mentioned by individuals and families attending the event.

<table>
<thead>
<tr>
<th>Professionals' View: Was the event useful for professionals?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes, 9 professionals found it useful. 1 professional thought it could be more useful.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Professionals' View: Was the event useful for those with ALD/AMN and their families?</th>
</tr>
</thead>
<tbody>
<tr>
<td>8 professionals found it useful, 1 thought it could be more useful.</td>
</tr>
</tbody>
</table>

Those with ALD/AMN and their families were also positive about the effect of the weekend on helping them to manage their own condition or that of a loved one. No respondents found the event to be Not Useful, with 63% giving it the highest possible rating of Very Useful.

When asked for comments to improve the usefulness of the event, individuals asked for more focus on the variety of possible symptoms of ALD and AMN, as well as symptoms faced by women. Others used the opportunity to praise the weekend as “perfect.”

100% of respondents may consider attending a future event. 94% answered ‘Yes’ to this question, with one ‘Maybe’ from an attendee hoping for more information on female symptoms.

These respondents were keen to return because they see the event as “absolutely fantastic.” One family “learnt more in 4 days than we have learnt...since diagnosis”

The event made individuals “realise [they] are not alone fighting this condition.”
Most respondents have attended all possible events since discovering ALD Life; 68% of those who answered the survey. Reasons given for missing a previous event included difficulties in coping with bereavement, reluctance to meet others with the condition and other personal reasons. This supports evidence that attendees are keen to return to the Community Weekend where possible; lack of value of the event was not given as a reason for missing a previous event.

<table>
<thead>
<tr>
<th>Reason</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>No, I have attended all events since I found ALD Life</td>
<td>68%</td>
</tr>
<tr>
<td>I did not want to meet others with the condition</td>
<td>6%</td>
</tr>
<tr>
<td>I am bereaved and did not feel I could cope</td>
<td>6%</td>
</tr>
<tr>
<td>The location of previous events has been too difficult for me and my family</td>
<td>3%</td>
</tr>
<tr>
<td>I found out about the event(s) at too short notice</td>
<td>3%</td>
</tr>
<tr>
<td>Other</td>
<td>15%</td>
</tr>
</tbody>
</table>

Families were asked to comment on how much they agreed or disagreed with statements relating to their own or their loved one’s condition.

These questions were similar to those asked before the event through the Booking Form; as shown below questions were not identical. This is due to changes in staffing during this process.

<table>
<thead>
<tr>
<th>Booking form statement</th>
<th>Feedback form statement</th>
</tr>
</thead>
<tbody>
<tr>
<td>I feel confident about caring for a loved one with ALD/AMN</td>
<td>I feel confident about caring for a loved one with ALD/AMN</td>
</tr>
<tr>
<td>I feel in control of my ALD/AMN</td>
<td>I feel in control of my/ my loved one’s ALD/AMN</td>
</tr>
<tr>
<td>I sometimes feel isolated because of my or my loved one’s ALD/AMN</td>
<td>I feel isolated because I do not know others with ALD/AMN</td>
</tr>
<tr>
<td>My family and I have the support that we need</td>
<td>My family and I have the support we need to cope with ALD/AMN</td>
</tr>
<tr>
<td>There is a good information flow between professionals and families living with ALD/AMN</td>
<td>I share relevant information with other families about ALD/AMN</td>
</tr>
<tr>
<td>Professionals have a good understanding of the lives of people living with ALD/AMN</td>
<td>I feel isolated because professionals around me do not know about ALD/AMN</td>
</tr>
<tr>
<td>I find it easy to communicate with professionals regarding my ALD/AMN or on behalf of a loved one</td>
<td></td>
</tr>
</tbody>
</table>
Comparing answers from these forms suggests that families who attended the conference and completed the survey feel confident and supported in coping with ALD/AMN, as demonstrated in the two examples below.

While 57% felt confident about caring for a loved one before the weekend (either ‘Completely’ or ‘Mostly’ agreeing), almost 1/3 respondents felt that this had improved following the Weekend. With all respondents claiming to Agree at least as much as before (or claiming that the question was not applicable), the 4% who originally did not agree do not seem to be represented.

22% felt more certain that their family had the support needed after the weekend. Most respondents selected ‘Agree as much as before’ in response to this question. It is not clear from the above chart if the feedback has been given by a representative selection of attendees: i.e. those who did not feel supported before the weekend may not have given feedback.

The below table addresses this, comparing booking form responses to feedback responses for all who completed both surveys.
This shows the feedback response to be representative of how attendees feel about family support: all booking form options are shown here. Only one person who disagreed with the statement indicated that they “Disagree as much as before;” although those claiming to “Agree as much as before” may be expressing continued disagreement due to ambiguity in the question.

To make these questions more valuable in the future, statements on booking forms and feedback surveys should be identical, with a follow up question asking if respondents felt differently about their condition as a result of the event. Further comments on increasing the validity of this question are included in the Survey Feedback section of this report.

Comments suggested these questions were difficult to answer. This is due to:

- short time period between the event and the feedback survey
- complexity of questions asked
- involvement of other factors
CONCLUSIONS

Although the response to this survey has been very positive, there are some key lessons to be learned for future events based on this feedback:

- **Issues with technology** prevented presentations from being recorded for those who could not attend them all, as well as causing delays and distractions in issues with microphones and computers.
- **Technical jargon** used in presentations sometimes made them difficult to understand.
- **Female symptoms** were mentioned many times by several survey respondents as an area which should receive more attention in future events. The high frequency of comments and feedback relating to female symptoms highlights that women who are carriers of or have symptoms of AMN still feel their issues are neglected. Some women disagreed with information from research presented at the event. A coping session for affected women was suggested.
- **Layout of the presentation room** received both positive and negative feedback. The decision to keep this layout of circular tables and screens not directly behind presenters should be considered carefully for future events.
- **Buffet-style meals** at this year’s event were in response to difficulties in bringing food to tables in previous years. This also received mixed feedback, however, due to access difficulties for those with mobility scooters and some dissatisfaction with the choice of food available, particularly in relation to food intolerances.
- **Professional Round Table sessions** did not always have strict agendas or did not keep to these. This allowed conversations to move away from the agreed focus of the meeting.

This survey revealed a strong willingness of attendees to contribute towards accommodation costs in the future, as well as some enthusiasm for fundraising. This should be taken into consideration when planning future events.

The ALD Life Community Weekend 2018 was clearly a highly valuable event for both affected individuals and professionals. Comments on this often focus on the value of meeting others in a similar position, reducing feelings of isolation. Discovering more about the condition and new developments in research and treatment are also important to attendees.

“No amount of reading or researching can actually compare to actually speaking to families managing day to day with this condition”

“I found the whole weekend very humbling talking to people/families”

“We would be lost without ALD Life”
SURVEY FEEDBACK

In this year’s survey, respondents were asked for their feedback on the survey itself, in order to improve accessibility of future surveys by diagnosing and resolving issues.

These comments were generally positive, describing the survey as “easy to use,” although there were some who faced difficulties in completing it with a mobile device. Although some described the survey as long, it was recognised that this was necessary in order to capture the complexity of the event. The questions allowed a “good variety of answers to choose from and room for extra comments.”

The ability to give feedback at the event itself was an important outcome of this question, as “there is no substitute for getting an instant feedback.” Some respondents felt that this would have made them more able to give more detailed, accurate feedback on the presentations in particular. This may require the use of paper forms in future.

There were some examples of questions being answered wrongly, leading to errors in results which have been corrected where possible. These resulted for example in professionals answering questions designed for affected individuals and their families.

This shows the need for clear, easy to understand questions. The addition of an ‘Other’ option allows respondents to create their own answer if none of those given are applicable, but this should be removed in cases where all possible groups are covered. Failing to do this, particularly in questions where the answer given affects the following question, makes the survey weaker and less easy to interpret. For example, when asked if they had attended the event to seek support for a child or relative with ALD/AMN, many created their own answers even where these aligned closely to those available. Those who selected professional involvement or support for their own condition were then asked appropriate questions; all others were directed to questions relating to care of others. Those creating their own answers were automatically directed to questions relating to care of others, which was often not appropriate, as these should have answered questions for professionals.

Questions asking how far individuals agree with statements relating to their management of their condition could have been made more valuable and much clearer by linking these more strongly with questions asked in the Booking Form.

The phrasing of feedback questions causes some confusion; it is not clear if those who selected ‘Disagree’ on the booking form and ‘Agree as much as before’ on the
feedback survey now feel positively about the statement, if they believe that they agreed with it before the event, or if their response has not changed. This is because the feedback form question is attempting to establish how far the respondent agrees with the statement now and in the past; it was not written in consideration of the fact that attendees would already have provided information on their response before the Weekend.

Further confusion was caused by questions which asked if respondents agreed with negative statements. This graph relates to the statement “I sometimes feel isolated because of my or my loved one’s ALD/AMN” (OR “I feel isolated because I do not know others with ALD/AMN”). Results do not show clearly that feelings of isolation have increased or faded; this could be due to the previously mentioned issue of confusion with “Agree/Disagree as much as before,” as well as due to confusion over agreement with a statement suggesting negative feeling.

It is not possible to obtain 100% participation in feedback surveys, nor to guarantee that respondents will be representative of all attendees. This question showed that the survey was answered by a diverse range of people, with differing opinions on how they were managing their condition before the weekend. This is a strength of the survey, demonstrating it to be representative.

Report written by Clare Dickson, Monitoring and Evaluation Officer
Photos by Ann Bloom [http://www.annbloomfoto.com/]
June 2018
We welcome your feedback about the ALD Life Community Weekend 2018. We will use your feedback and comments to see how we can improve our Community Weekends in the future and make sure you get the information, help and support that you need.

Please only complete the form once.

* Required

1. Name *

2. Are you happy for ALD Life to use any of your comments in our communications and fundraising materials? *

   We will not use your name if using your comments for any purpose. Your comments help us to improve future events, to encourage others to attend and to attract funds to keep our events running.

   Mark only one oval.

   ○ Yes
   ○ No

3. Total number in your party *

   Mark only one oval.

   ○ 1
   ○ 2
   ○ 3
   ○ 4
   ○ 5
   ○ 6
   ○ 7
   ○ 8

4. Number of children in your party (16 or under) *

   Mark only one oval.

   ○ 0
   ○ 1
   ○ 2
   ○ 3
   ○ 4
   ○ 5
   ○ 6
   ○ 7
   ○ 8
5. **Age range of guests in your party** *
   Please tick all that apply
   Check all that apply.
   - 0-16 years
   - 17-24 years
   - 25-44 years
   - 45-64 years
   - 65+

### About You

6. **Your diagnosis** *
   If you are caring for someone with ALD/AMN, questions on their diagnosis will follow. Please select the options which most apply to you personally. If you are attending the conference in a professional capacity (e.g. doctor, researcher, pharmaceutical company) please select Professional.
   Check all that apply.
   - Female Carrier
   - Asymptomatic ALD
   - Symptomatic ALD
   - Post-BMT
   - AMN
   - Addison's Disease
   - Lost a child/relative/partner to ALD/AMN
   - Caring for someone with ALD/AMN
   - Unaffected
   - Professional
   - Other: ____________________________

7. **Did you attend the conference to seek support for a child or relative with ALD/AMN?** *
   If you are supporting a child or relative and also coping with your own symptoms, or if you have also lost a relative to ALD/AMN, please select Option 1, 'Yes.'  
   **Mark only one oval.**
   - Yes, I am seeking support as a parent, relative or carer of someone with ALD/AMN  
     Skip to question 24.
   - No, I am only seeking support for my own ALD/AMN  
     Skip to question 25.
   - No, I am only seeking support after losing a child or relative with ALD/AMN  
     Skip to question 25.
   - No, I have a professional involvement in ALD/AMN (e.g. Physician, Researcher, Pharmaceutical representative)  
     Skip to question 8.
   - Other: ____________________________  
     Skip to question 24.
Professionals
The following questions are for those attending the ALD Life Community Weekend in a professional capacity, e.g. doctors, researchers, pharmaceutical representative

8. What were your main reasons for attending the ALD Life Community Weekend? *
   Check all that apply.
   - Presenting research or information on ALD/AMN
   - Meeting other professionals to discuss ALD/AMN and share knowledge
   - Meeting families of those affected by ALD/AMN
   - Learning more about the work of ALD Life as an organisation
   - Other: ____________________________

9. Based on your reasons for attending, did the event meet your expectations? *
   Mark only one oval.
   - Exceeded expectations
   - Met expectations
   - Some expectations met
   - Did not meet expectations
   - Not sure
   - Other: ____________________________

10. Comments

   _______________________________________________________________________

   _______________________________________________________________________

   _______________________________________________________________________

11. The Professionals' Roundtable events are intended to bring professionals together to share information and updates on ALD/AMN. Was this a useful format for this purpose? *
    Mark only one oval.
    - Very Useful
    - Useful
    - Moderately Useful
    - Slightly Useful
    - Not Useful
    - N/A- did not participate

12. Comments on the Professionals' Roundtable, and any suggestions for improvement

   _______________________________________________________________________

   _______________________________________________________________________

   _______________________________________________________________________
13. **Was this your first ALD Life Community Weekend Event?** *
   *Mark only one oval.*
   - Yes, this is my first event  
   - No, I have attended a previous event

14. **How does this event compare to previous ALD Life Community Weekends that you have attended?** *
   *Mark only one oval.*
   - Much better than previous event(s)
   - Better than previous event(s)
   - As good as previous event(s)
   - Not as good as previous event(s)
   - Much worse than previous event(s)
   - Other: __________________________

15. **Comments**

   ______________________________________________
   ______________________________________________
   ______________________________________________
   ______________________________________________

16. **Do you feel that your feedback from previous events has been taken in to account for this event?** *
   *Mark only one oval.*
   - Yes, I know that my feedback has made a difference
   - My feedback seems to have made a difference
   - My feedback might have made a difference
   - My feedback has not made any difference
   - I cannot tell if my feedback has made any difference
   - I did not give feedback at a previous event
   - I did not make suggestions in my previous feedback
   - Other: ______________________________________

17. **Would you be interested in attending an ALD Life Community Weekend event in the future?** *
   *Mark only one oval.*
   - Yes
   - No
   - Maybe
18. Why, or why not?


19. Overall, do you think the ALD Life Community Weekend was useful to you and other professionals? *
Mark only one oval.

☐ Yes
☐ No
☐ Could be more useful
☐ Don't know

20. How can we improve the event to make it more valuable for you and other professionals?


21. Overall, do you think the ALD Life Community Weekend has been useful to those with ALD/AMN and their families? *
Mark only one oval.

☐ Yes
☐ No
☐ Could be more useful
☐ Don't know

22. Finally, how can we improve the event to make it more valuable for those with ALD/AMN and their families?


23. Please use this section for any feedback on this survey: how easy to use, how useful, any suggestions

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

Stop filling out this form.

Caring for someone with ALD/AMN

24. If you care for someone with ALD/AMN, please select all options which apply to them *

Check all that apply.

☐ Asymptomatic ALD
☐ Addison's Disease
☐ Symptomatic ALD
☐ Post-BMT
☐ AMN
☐ N/A- I do not care for someone with ALD/AMN
☐ Other: __________________________

Your expectations

25. What were your main reasons for attending the ALD Life Community Weekend? *

Check all that apply.

☐ Learning more about how myself and my family can cope with ALD/AMN
☐ Learning more about ALD/AMN (e.g. research advances, diagnosis, other leukodystrophies)
☐ Socialising with friends/ Enabling my child to socialise with friends
☐ Meeting other families with ALD/AMN
☐ Meeting doctors and professionals who are knowledgeable about ALD/AMN
☐ Sharing experiences of ALD/AMN with other families
☐ Other: __________________________

26. Based on your reasons for attending, did the event meet your expectations? *

Mark only one oval.

☐ Exceeded expectations
☐ Met expectations
☐ Some expectations met
☐ Did not meet expectations
☐ Not sure
☐ Other: __________________________
27. Comments

The Venue, Presentations and Activities

28. How satisfied were you with the venue? *
Mark only one oval per row.

<table>
<thead>
<tr>
<th></th>
<th>Very satisfied</th>
<th>Satisfied</th>
<th>Neutral</th>
<th>Dissatisfied</th>
<th>Very dissatisfied</th>
<th>N/A</th>
</tr>
</thead>
<tbody>
<tr>
<td>Meeting Rooms</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hotel Facilities</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Accessible Facilities</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Meals</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Location</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hotel Staff</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>ALD Life</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Staff/Volunteers</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

29. Additional comments


30. A) In terms of your knowledge about ALD/AMN, how useful were the following presentations to you? *
Mark only one oval per row.

<table>
<thead>
<tr>
<th>Presentation</th>
<th>Very Useful</th>
<th>Useful</th>
<th>Moderately Useful</th>
<th>Slightly Useful</th>
<th>Not Useful</th>
<th>Not relevant to me</th>
<th>N/A- did not attend</th>
</tr>
</thead>
<tbody>
<tr>
<td>Management of Symptomatic Boys: Dr Alasdair Parker</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>BMT/Gene Therapy: Dr Robert Chiesa</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Monitoring Asymptomatic Boys: Dr James Davison</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Research on gene therapy for AMN: Dr Florian Eichler</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Update on New Born Screening (NBS) in the USA: Dr Ann Moser</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
31. **B) In terms of your knowledge about ALD/AMN, how useful were the following presentations for you?** *

*Mark only one oval per row.*

<table>
<thead>
<tr>
<th>Presentation</th>
<th>Very Useful</th>
<th>Useful</th>
<th>Moderately Useful</th>
<th>Slightly Useful</th>
<th>Not Useful</th>
<th>Not relevant to me</th>
<th>N/A-did not attend</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sports and ALD: Dr Gerald Raymond</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Genetics and ALD: Dr Gemma Chandratillake</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Addison's Disease Management: Dr Ved Arya</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bladder Issues for AMN Patients: Dr Sara Simeoni</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Life after Bone Marrow Transplant: Rhys Long</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female Symptoms: Dr Woulter van Ballegoij</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

32. **C) In terms of your knowledge of ALD/AMN, how useful were the following presentations for you?** *

*Mark only one oval per row.*

<table>
<thead>
<tr>
<th>Presentation</th>
<th>Very Useful</th>
<th>Useful</th>
<th>Moderately Useful</th>
<th>Slightly Useful</th>
<th>Not Useful</th>
<th>Not relevant to me</th>
<th>N/A-did not attend</th>
</tr>
</thead>
<tbody>
<tr>
<td>Symptom Management for Adult Males and update on adult BMT in the UK: Dr Robin Lachmann</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Priorities for AMN men: Raremark</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Transition to adult services: Dr Elaine Murphy</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>The ALD Database: Dr Stephan Kemp</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>NeuroVia NV1205 Clinical Trial: Dr Masoud Mokhtarani</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Minoryx MIN-102 clinical trial: Dr Uwe Meya</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Research Q&amp;A</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

33. **Additional comments: Please help us to improve presentations which you found less useful**

__________________________________________________________________________

__________________________________________________________________________

__________________________________________________________________________

__________________________________________________________________________
34. **Additional comments: Are there any other topics you would have liked to include?**

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

35. **If you were unable to attend any of the sessions, are you hoping to watch the recordings online?** *

If you were not aware of the recordings before being asked this question, please tick Option 1 “I was not aware of the recordings” as well as your answer. Recordings will be available on the ALD Life website shortly. 

*Check all that apply.*

- [ ] I was not aware of the recordings
- [ ] Yes, I intend to watch at least one recording
- [ ] I am not able to access/view/listen to online recordings
- [ ] I do not want to watch recordings online
- [ ] I do not have time to watch the recordings
- [ ] The session(s) I missed were not of interest to me
- [ ] Other: ________________________________________________________________

36. **In terms of managing your/your loved one’s condition, how useful were the following for you?** *

*Mark only one oval per row.*

<table>
<thead>
<tr>
<th></th>
<th>Very Useful</th>
<th>Useful</th>
<th>Moderately Useful</th>
<th>Slightly Useful</th>
<th>Not Useful</th>
<th>Not relevant to me</th>
<th>N/A- did not attend</th>
</tr>
</thead>
<tbody>
<tr>
<td>Q&amp;A Sessions</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Opportunity to meet doctors</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mindfulness coping workshop</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Emergency hydrocortisone injection training</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Transition to adult services workshop</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Supporting ALD Life through social media</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

37. **Additional comments: Did you have any difficulties with these sessions, or do you have suggestions to improve them?**

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
### Activities

38. **Please rate the social activities provided at the ALD Life Community Weekend** *
   
   *Mark only one oval per row.*

<table>
<thead>
<tr>
<th>Activity</th>
<th>Excellent</th>
<th>Very Good</th>
<th>Good</th>
<th>OK</th>
<th>Poor</th>
<th>Very Poor</th>
<th>N/A- did not take part</th>
</tr>
</thead>
<tbody>
<tr>
<td>Friday Night Icebreaker Quiz</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Saturday Night Casino</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sunday Night Bridge Building</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

39. **Additional comments on activities**

   
   
   
   

40. **If you or your child participated in any of the activities for young people, please rate them here** *
   
   *Mark only one oval per row.*

<table>
<thead>
<tr>
<th>Activity</th>
<th>Excellent</th>
<th>Very Good</th>
<th>Good</th>
<th>OK</th>
<th>Poor</th>
<th>Very Poor</th>
<th>N/A- my child did not attend</th>
<th>N/A- there were no children in my party</th>
</tr>
</thead>
<tbody>
<tr>
<td>O2</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Activity Room</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Keir Hardie Recreation Ground</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Swimming</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

41. **Additional comments: Feedback on these activities and ideas on future activities**

   
   
   
   

### Future Events

42. **Was this your first ALD Life Community Weekend Event?** *
   
   *Mark only one oval.*

- [ ] Yes, this is my first event  
  
  *Skip to question 46.*

- [ ] No, I have attended a previous event  
  
  *Skip to question 43.*

- [ ] Some of my party had attended a previous event  
  
  *Skip to question 43.*
43. How does this event compare to previous ALD Life Community Weekends that you have attended? *
   If you have not attended a previous event, but someone else in your party has done so, please ask them or consider their opinion for this question. If you are unable to do this, please select ‘Unsure of opinion of previous attendee(s)’
   Mark only one oval.
   - Much better than previous event(s)
   - Better than previous event(s)
   - As good as previous event(s)
   - Worse than previous event(s)
   - Unsure of opinion of previous attendee(s)
   - Other:

44. Do you feel that your feedback from previous events has been taken into account for this event? *
   Mark only one oval.
   - Yes, I know that my feedback has made a difference
   - My feedback seems to have made a difference
   - My feedback might have made a difference
   - My feedback has not made any difference
   - I cannot tell if my feedback has made any difference
   - I did not leave any feedback at a previous event
   - I did not make suggestions in my previous feedback
   - Other:

45. Comments on previous events and feedback

Reasons for not attending
46. Has anything prevented you from attending an event in the past? *
   If you have been unable to attend events because of their timing in relation to your own schedule, or you had not heard of ALD Life before this event, please select Option 1 (I have attended all events since I found ALD Life)
   Mark only one oval.
   - No, I have attended all events since I found ALD Life Skip to question 48.
   - I did not want to meet others with the condition Skip to question 47.
   - I did not want my child to see others with the condition Skip to question 47.
   - I am bereaved and did not feel I could cope Skip to question 47.
   - The location of previous events has been too difficult for me and my family Skip to question 47.
   - I found out about the event(s) at too short notice Skip to question 47.
   - Other: Skip to question 47.
47. Why did you decide to attend the ALD Life Community Weekend this year? *
Check all that apply.

☐ Hearing about the event from ALD Life
☐ Hearing about the event from other families with ALD/AMN
☐ Support received from ALD Life
☐ Changes in my/my loved one's condition
☐ Other: ____________________________

ALD Life Community Weekends- Future

48. Would you consider attending an ALD Life Community Weekend in the future? *
Mark only one oval.
☐ Yes    Skip to question 50.
☐ No     Skip to question 49.
☐ Maybe  Skip to question 50.

49. Why not?

________________________________________
________________________________________
________________________________________
________________________________________

Skip to question 53.

50. Why?

________________________________________
________________________________________
________________________________________
________________________________________

51. Would you be willing to fundraise for the next event? *
Fundraising support can be provided to help with this
Mark only one oval.
☐ Yes
☐ No
☐ Maybe
☐ Other: ____________________________

52. Would you be willing to contribute to your accommodation at a future event? *
Mark only one oval.
☐ Yes
☐ No
☐ Maybe
☐ Other: ____________________________
Final Thoughts

53. **Overall, how useful do you feel the event has been in terms of managing your/your loved one's condition?**

   *Mark only one oval.*

   - [ ] Very Useful
   - [ ] Useful
   - [ ] Moderately Useful
   - [ ] Slightly Useful
   - [ ] Not Useful

54. **Do you have any comments or suggestions on how to make the event more useful for you and your family?**

   

   

   

55. **Please consider if you agree with these statements more or less following the ALD Life Community Weekend**

   *Mark only one oval per row.*

<table>
<thead>
<tr>
<th>Agree more than before</th>
<th>Agree as much as before</th>
<th>Agree less than before</th>
<th>Disagree less than before</th>
<th>Disagree as much as before</th>
<th>Disagree more than before</th>
<th>N/A</th>
</tr>
</thead>
<tbody>
<tr>
<td>I feel confident about caring for a loved one with ALD/AMN</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I feel in control of my/my loved one's ALD/AMN</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>My family and I have the support we need to cope with ALD/AMN</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I share relevant information with other families about ALD/AMN</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I feel isolated because I do not know others coping with ALD/AMN</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I feel isolated because professionals around me do not know about ALD/AMN</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
56. Additional comments on these statements


57. Please use this section for any feedback on this survey: how easy to use, how useful, any suggestions


