

## QUEENSLAND REPORT

### The Inaugural ALD Charity Collaboration 18<sup>th</sup>/19<sup>th</sup> July 2011, San Clemente USA

The Inaugural ALD Charity Collaboration was held in San Clemente on the 18/19<sup>th</sup> of July 2011. The attendees were from the following organisations:

1. ALDlife
2. BAHBAD
3. Fight ALD
4. Stop ALD
5. ALDS
6. US Myelin Project
7. Cure ALD

Apologies from:

8. BVL
9. ALD Foundation
10. Little Warriors
11. Oliver's Army
12. ELA

#### **Purpose:**

1. To inform other ALD charities of the structure, aims, resources etc of each charity
2. To share ideas or other information that will help each charity
3. To understand how we can work together for agreed goals

#### **Introductions:**

Each charity presented on their charity, its aims and what they hoped to get from the collaboration and other organisations. BVL and Little Warriors were represented and reference was made to the excellent work carried out by Oliver's Army.

#### **Meeting output:**

It was agreed by all that in order for us to collaborate further and be a stronger unit that a formal alliance should be formed. Each charity has its own strengths and resources and these would be exploited by this alliance. Our desire to `get on with things` was reflected in the decision not to form a new company or charity but merely a web portal that would be a `one stop shop` for ALD and AMN patients, carriers, carers and medical representatives. Although funds raised would be pooled they are likely to be through Cure ALD and not the new Alliance therefore no formal appointments are necessary.

#### **Actions:**

The actions below have been broken down in to themes and while we should aim to have them completed by the next meeting realistically some will be later.

#### **Patient Support:**

In addition to the existing resources within the group the following was agreed:

- a) **One Pagers:** A one pager would be available on the new website for patients to take in to Drs/Physicians if they do not feel the Dr has an adequate understanding of the diseases.

**Action:** Fight ALD has one available already on her website.

**b) On Line Doctor:** To investigate the possibility of on line Neurological support via `Just Answer` or other means.

**Action:** ALDlife to investigate further.

**c) On Line Community:** To provide an on line feedback (FB) type of community that is moderated, structured correctly (with threads) and therefore endorsed by AGA. It was felt that ALD Support was proving dangerous with `cures` or treatments being discussed in an uncontrolled fashion. The more our website contained accurate information the less this should happen.

**Action:** ALDlife to review existing ones although consideration should be given to creating our own which would be moderated by us.

**d) FAQs:** These should be on the new website too although was acknowledged they would evolve and be split into different groups as time went by.

**Action:** Stop ALD to send current FAQs to ALDlife and US Myelin Project to start with to incorporate into new website.

**e) Bridge support:** To investigate the possibility of providing a quarterly bridge/conference facility for patients/carriers or carers to dial in with a question where a specialist would be available to comment directly.

**Action:** ALDlife to investigate.

**f) List of specialists:** To provide (on the website) a list of medical specialists who are familiar with the diseases. This is to help those who struggle to get support from their Drs and therefore can ask to speak to a better informed Doctor.

**Action:** ALDlife to post on ALD Support group and collate responses.

**g) Collateral:** All new leaflets and other collateral should be `branded` with the new AGA logos as appropriate.

**Action:** ALDlife and US myelin Project to note.

**h) Route maps:** It was explained ALDlife were working on documenting the journey from diagnosis to treatment and would share with the group when ready. However Fight ALD agreed to working on these for our group too as the US journey would be different to the UK and other countries. Consideration should be given to getting a donor match at diagnosis and getting friends and family to donate at this time.

#### **Awareness:**

**a) Leaflets:** It was agreed Fight ALD should continue with her excellent work in travelling the US but should widen her audience to avoid duplication of effort and maximise her time.

**Action:** Fight ALD to incorporate a more medical slant to her existing leaflets by using the Stop ALD ones. This would mean she has a greater audience with less effort i.e. only delivering one leaflet.

**b) Bracelets and slogans:** It was agreed Fight ALD and the slogan `Fighting illness through education` should be used by the group for consistency.

**c) AGA promotion:** No discussion took place during the meeting around how the Alliance should be promoted. We should consider speaking at the next ULF event, ELA equivalent and also Neurological or other medical magazines.

- d) Specific messages:** In addition to general disease awareness we should consider specific messages targeted at Endocrinologists e.g. 50% of Addison's diagnosis result in an ALD diagnosis but too late to allow the child to have a BMT. ADHD is a similar story although statistically not to the same degree.

**Action:** ALDlife to secure readymade article used previously by KKI. This would be part of our promotional plan to be discussed further.

- e) Paediatric Training:** Fight ALD explained she was working with Dr Charlie Peters on ensuring ALD gets an appropriate focus in training.

**Action:** Fight ALD to share the output of her activity at the next meeting.

- f) Myelin Project website:** US Myelin Project agreed to look in to the MYP website having a dedicated focus on ALD and AMN.

### **Newborn Screening (NBS):**

The ULF conference highlighted the need to get NBS for ALD as soon as possible. A trial had been completed in Maryland while there was a financial challenge in acquiring equipment (\$500k). Additionally there were several people seemingly making moves in this area already although the extent was not known. The methodology for blood spotting was sound which enables the testing for ALD to be cheap, fast and effective. The UK had started down this path already and would share any insight as appropriate.

**Action:** BAHBAD to pursue this for California using Fight ALD and US Myelin Project and ALDS to update the group on his discussions with MLD representatives in America

### **Events:**

- a) Hammer Fest (MYP) Fundraiser on Sep 18<sup>th</sup>.**

**Action:** US Myelin Project to send invite to BAHBAD

- b) MYP AGM in Paris on October 14<sup>th</sup>:**

**Action:** US Myelin Project to send details to ALDlife

- c) `Amble for ALD`:** Sponsored Walk on 10<sup>th</sup> September. Short notice but all members are encouraged to take Part, get friends and family to organise their own or simply promote on their websites. Just a couple of miles for children with a MacDonald's or other appealing destination for walkers would be fine. The plan is for a single day a year for all ALD charities to have a single endorsed event.

**Action:** Everyone to join in! Would suggest funds are given to each charity for now.

### **AGA Website:**

ALDlife shared his thoughts on the structure of the site and gave us all a hand written view too. All agreed the format would be fine. It would be a single portal with everything you need to know but underpinned by us all. Links to all our charities and other appropriate ones would be available. The only question would be who would develop the website. Stop ALD had contacts with volunteers who would build it for free while US Myelin Project (MYP) could do this too but would rightly need paying for his time. US Myelin Project however is connected to the group and his involvement in the discussions so far would give him an advantage. In the interests of fairness it was agreed MYP and ALDlife could review the requirements and provide some kind of estimate by the next meeting. The site should also include videos which MYP has sent already, a calendar of events and also a focus on BMT/Donor information. The name was agreed to be ALD and AMN Global Alliance.

**Action:** MYP and ALDlife to consider name and implications for search engines (e.g. ALD and AMN or ALD-AMN) and provide an estimate for web development. Should we decide to pay UMP to do the development then the costs would be shared across the group.

#### **Fundraising:**

- a) **Fundraising pack:** Lots of good ideas were shared and each group shared the approximate amount raised by them already. The website should include fundraising tips including a fundraising pack which ALDlife has already. MYP has sent a generic 2010 fundraising tips document which ALDlife agreed he would combine to form a single AGA branded fundraising pack.

**Action:** ALDlife to send the UK document then ALDlife and MYP to merge the two.

- b) **Pooling of funds:** Some discussion on the best way to pool and manage funds without having to create a new account with the associated governance. It was agreed we should use Cure ALD account as it has governance already. It was also agreed that the use of these funds would be limited to global and not country specific.

**Action:** Cure ALD to ensure this is acceptable and to inform us of any shortfalls. MYP to check on legal implications of this.

- c) **Paul Newman Charity:** ALDS explained this group had donated to them and could be a useful source of funding. All to note

- d) **Australian Rugby Player:** Stop ALD talked about a contact she had with a famous Australian Rugby player that could be used for ALDS.

**Action:** Stop ALD to send details to ALDS.

#### **Research:**

- a) **Funding:** It was agreed we would all like to fund research if possible but were unclear who and how. MYP are already scheduled to review research proposals in October while smaller projects required funding but were not on the MYP project radar currently. It was agreed that the MYP would review the proposals as planned but would report back to us any shortfalls in funding and we would consider contributing. It was also agreed that Stop ALD's strength in this field should be used as much as possible...

**Actions:** Stop ALD to collate one pagers from known smaller projects and send to MYP by mid September.

MYP to submit these one pagers for MYP consideration and report back output to the group after October.

- b) **Research co-ordination:** ALDlife explained he was already in the process of `recruiting` a coordinator who could compile all ALD/AMN specific research activities so we had a single view and a single point of contact.

- c) **AMN Women research:** Fight ALD voiced some concern there was not enough research being done for AMN Women despite the difference in how the disease was progressed in medical terms.

**Action:** MYP to contact DR Naidu to get her comments on how this should be addressed.

**Theme `Champions`:** A suggestion after the meeting had closed would be to appoint champions or lead in certain activities. It doesn't mean a great deal of extra work but would be sensible to have MYP as our BMT/Donor rep for example and to be responsible for that content on the website.

**Next Meetings:**

An additional meeting was held on the 19<sup>th</sup> of August which advanced most of the topics raised and agreed upon at the prior meeting. The name was determined as the ALD Global Alliance (AGA). The website creation is to start immediately. The logo design is still to be decided. The ELA understands that the AGA is supporting the International community and that “learnings” will be shared by all countries, which of course includes Australia. The next meeting is scheduled for October.

I trust that this rather lengthy report allows those affected by ALD/AMN to see that there is action being taken at both an Australian and Global level.

Kind regards

**Bob Wyborn**  
**ALDS QLD STATE REP**