

## AGSD-UK Main Event report

The event attracted over 100 people affected by a range of GSDs over the course of the weekend.

The programme was developed in partnership with people affected by GSDs and was aligned with our three strategic goals relating to:

- Support across the community
- Help with living well
- Better treatments and service access

The specific aims of the event were as follows:

- People affected and their families are connected to sources of peer support and feel less isolated
- Community members are better informed about developments in the GSD field
- People are equipped with information and approaches to improve self management and well being
- People affected are better able to navigate services and access support
- The event reaches and engages all sections of the GSD community and is safe and accessible for all

With the above in mind, the programme was designed to include opportunities for:

- meeting and sharing experiences with other people affected
- hearing from leading experts about latest research and developments in treatment and management of the different GSDs
- trying out new therapeutic activities
- discussing key topics relating to life with the condition

The evaluation forms completed showed that:

- 98% said the event enabled them to connect with others with similar experiences
- 98% said the event gave them the chance to gain tips about living with GSDs
- 96% said the event allowed them to become better informed about research and developments in the field of GSDs
- 95% said the event provided the opportunity to get information about support and services that are available
- 100% said they had fun and enjoyed themselves

We have been overwhelmed by the volume of positive feedback received, of which the following are just a few typical examples:

- Really loved the whole event...Content of the programmes was spot on. Nice to meet with Pompe people and with mixed group GSDs...Loved the drums and the art.
- It was great to hear from the experts!
- A really important event that should continue
- It was a well organised, very informative event. Learnt more today than in the previous 50+ years since initial diagnosis
- Our first one, loved every minute. Thank you! We'll be back next year. I've learned more today than when my son was diagnosed

- 100% valuable. Well organised. Would love an event in this place again.
- Spot on excellent. Love to come again. Loved the raffle experience. Well organised. 100% 😊
- The organisers did a great job. Thank you
- Lovely to meet and talk with everyone again. Wonderful update and insight into the gene therapy trials
- An enjoyable weekend and very productive. Thanks to the sponsors and organisers. The music programme (i.e. the harp concert) was one of the greatest highlights
- Very good meeting. Well organised
- Patient stories were really brill- great to see their individual experiences. Thanks!
- Absolutely excellent conference- enjoyed myself. Thankful for all the hard work. 10/10 (plus a nice little picture of a flower!)
- Learned more about my disease today than I ever have before
- Very well organised and presented
- Great to listen to the guys at the start with their experiences.
- Overall found the day very wonderful and looking forward to the next
- Great organisation. Informative programme and social opportunity to connect with others. Venue and food spot on
- Good forum for networking. Good to be back in person!
- Excellent venue and meeting. Thank you!
- As a grandparent of a child with GSD3b, it has been a lovely opportunity to meet others and gain greater understanding. Understanding in both lived experience and the nature of progress of the disease. I would give it 5 stars. The venue and atmosphere added a very positive dimension to the whole weekend
- I thoroughly enjoyed the whole event. Good mix of informative, practical and what we needed. Great to meet other fellow McArdleites.
- It was great to meet more people this time and get involved in more activities. Many thanks.
- Fabulous weekend! ...Loved the whole conference. Great speakers and workshops.
- It was a very positive weekend. Informative and fun

Funding from SSIEM meant we were able to support identified families on low incomes and professionals early in their careers to attend. This was greatly appreciated:

- 'Being able to attend the Main Event was so important to me and my family. We live miles from anyone else and without the help with travel and accommodation this wouldn't have been possible. Time spent with others in a similar situation is priceless'.
- '...it was lovely to meet the AGSD community and have a chance to engage with everyone. I really enjoyed speaking with all the attendees.'

AGSD-UK is extremely grateful to SSIEM for helping to make this an accessible and successful event.