

Hi Nic and everyone at SSIEM,

I am writing to let you know that our rescheduled Zellweger UK Family Conference went ahead between Friday 21<sup>st</sup> July to Monday 24<sup>th</sup> July 2023.

We were so pleased to be able to finally hold the event and could not have done so without the support from yourselves, so thank you so much.

We had 16 families attend with children affected by Zellweger Syndrome, siblings and bereaved parents and siblings. We held it in The Manor and Ashbury Resorts in Devon as they provide conference facilities as well as many activities to entertain children and families in a safe environment.

We bought in extra activities to accommodate the deaf, blind children such as critters to touch and hold, music sessions and invited the charity SENSE to come along to help parents and children with sensory activities. We also bought in a face painter on the Sunday for everyone to enjoy.

We had metabolic nurses from the children's department Bristol hospital attend as well as a doctor to provide presentations and question and answer session with families. We also had scientists and PHD students come along to do presentations, meet the families to provide question and answer sessions.

We put your logo on our conference room banners and welcome packs as "thanks to our sponsors", we handed out 50 welcome packs that weekend. We cannot thank you enough for supporting us.

Your grant donation of £2616.66 received 01/06/2020 was put towards the cost of this event and we cannot thank you enough for your generous support. Please let me know if you require any more information about the weekend.

Kind regards  
Kerry Hughes  
Treasurer