

NATIONAL ADVISORY COUNCIL
TO
The Thalidomide Trust

Notes from NAC Q&A - 11 June 2021

An open Q&A session was offered to all beneficiaries on zoom to discuss and ask any questions about the NAC meeting on 11 May 2021. Text and video summaries of the May NAC meeting are available [here](#).

Use feedback@ttnac.org to stay in touch.

Issue raised	Action to follow up
Society members (who are not beneficiaries) should be able to give feedback on joint event, even if they didn't attend.	Carolyn to pass on to Ruth at the Society.
Funeral policy: People felt they had not been consulted properly on the new policy and felt let down that it didn't reflect what they had been promised by Trust staff in the past. Clarity is needed.	Rowland acknowledged and will take it back to NAC for discussion. There could be a survey question about funeral policy, which could give a mandate to review the policy. It could also be included in the 'shopping list' for the Diageo negotiations.
A question was asked by a beneficiary to the newsletter editor in February. No answer was received directly but it was answered by Rowland in the newsletter.	Rowland to follow up directly with the questioner.
Recently discovered thalidomide damage (not diagnosed in the past): Should beneficiaries have access to full body scans? Could evidence from this be helpful as part of Diageo negotiations (even if only from a limited number of people who want the scans)?	Carolyn explained H&W committee decision from 18 months ago on full body scans, as not everyone wants them. Individual beneficiaries can use their health grant for this if they wish. More info to go in newsletter. Carolyn and Rowland explained how evidence from the Care Costs review and HNAs will be used in Diageo negotiations, and how evidence has helped achieve progress in the past (eg. on major advances). For example, we may be looking for more funding for private referrals due to delays in NHS.
Grunenthal: Some beneficiaries have been applying for	Rowland noted concerns. This is being talked about within the NAC and they are in

<p>funding from Grunenthal and some have been successful. Shouldn't everyone be equally encouraged to do this? Would this affect future campaigning and negotiations?</p>	<p>correspondence with Grunenthal, but no more details can be shared yet.</p>
<p>Diageo: How will we feed in ideas for the next set of negotiations?</p>	<p>Rowland and Sarah to explore different ways for beneficiaries to contribute.</p>
<p>Future sessions:</p>	<p>Sarah to use feedback in planning next session and make sure no names are used in notes.</p>