

THE NATIONAL ADVISORY COUNCIL FACTSHEET

Q What is the role of the National Advisory Council (NAC)?

A The NAC is an elected, user-led group that exists to represent the beneficiaries of the Thalidomide Trust by working in partnership with trustees and staff. The NAC takes account of sometimes differing views, discusses and weighs up all the factors and makes recommendations to the trustees and management team on policy from a beneficiary perspective. The NAC seeks to work in the best interests of all beneficiaries and to advocate for resources that enable beneficiaries to meet their increasing financial, health and wellbeing and other needs.

Q How long do individual members serve on the NAC for?

A There are 12 members of the NAC, each serving a standard term of four years, all of whom must be Trust beneficiaries. An NAC member may serve for three consecutive terms, but they must then leave the NAC for at least one year before standing for election again.

Q How are NAC members elected?

A Each year, at least three places on the NAC are up for election. All beneficiaries can vote in a secret ballot by post or online. Each candidate produces a short manifesto in print and on video. The manifestoes are sent to all beneficiaries. The elections are held at the start of each year and the results are announced in April. The votes are counted by Trust staff, who cannot see which beneficiary has voted for which candidates.

Q Do NAC members get paid?

A No, NAC members are volunteers. In line with the Trust's expenses policy, NAC members can claim back reasonable expenses incurred in carrying out their roles, for example travel to meetings.

Q Do you need any special qualifications or knowledge to be on the NAC?

A No, just your lived experience, as well as the time and willingness to represent and work on behalf of the beneficiary community. There are people with many different backgrounds on the NAC – some working, some who have never worked, some who are now retired – and members from many different parts of the UK. The NAC benefits from a variety of skills and experience. All new NAC members are mentored and supported by a current member.

Q What do NAC members do?

A The NAC holds full meetings of all members twice a year, as well as an annual awayday and monthly conference calls. These meetings are facilitated by the Chair and Vice Chair, who are elected by the NAC. NAC representatives sit on the Trust's Health & Wellbeing Committee, Finance Committee, and Research Committee. On these committees, NAC representatives contribute as equal members, alongside staff and Trustees. NAC members are involved in the five year strategic planning process and in working groups set up to plan and implement new initiatives (such as the introduction of the new Exceptional Needs Fund) or important processes (such as planning for the recent Health Grant renewal).

All NAC members may be required to help on certain projects or fulfil other roles, such as website liaison, organising the beneficiary survey or planning events. For a full list of roles visit: www.thalidomidetrust.org/about-us/our-people/nac/who-does-what-on-the-nac. It's hard to say exactly how much work is involved in being on the NAC, but the time commitment can be significant as it includes preparing for and attending meetings, following up agreed actions, and communicating with beneficiaries.

Q Is campaigning part of the NAC's remit?

A Not directly, but they have an important oversight role. The Campaigns Team helps secure additional resources for beneficiaries by undertaking targeted, structured and lawful campaigns and several NAC members are part of the team. It is not a formal sub-committee of the Trust's Board of Trustees and can include beneficiaries who are not on the NAC, however it is accountable to both the Board of Trustees and to the NAC.

Q How does the NAC make decisions and recommendations?

A NAC members make decisions and recommendations to the Trustees by considering and discussing research or other information on a particular topic, and decisions are influenced by consultation with the beneficiary community. The NAC's position on a particular issue is taken with the aim of representing the best interests of the community as a whole. As with the wider community, NAC members will not agree with each other all of the time. All views are considered and discussed. However, once the NAC has made a decision or agreed a recommendation for the Trustees, all members are bound by that decision/recommendation.

Q How does the NAC seek to hear the views of the beneficiary community?

A For each twice-yearly NAC meeting, the agenda is sent by email or post to all beneficiaries who have opted into communications from the NAC so that they have the opportunity to feed in their views ahead of the meeting. A summary of the meeting is circulated afterwards and is available on the NAC section of the website. There is an online Q&A shortly after each meeting, where all beneficiaries can raise questions and make comments. Similar Q&A sessions are used to consult with beneficiaries on specific issues. Beneficiaries can email the NAC directly or raise questions in the NAC Facebook group.

There are also opportunities during face-to-face events to speak to NAC members, and to share opinions through the beneficiary survey which takes place every three years. The NAC recognises that there have been times when beneficiaries have not felt consulted and is seeking to improve this. Within the beneficiary community, there are many different – and sometimes conflicting – views held and the NAC seeks to listen to everyone, including those who may need more encouragement to come forward.

Q The NAC represents the beneficiary community, so why are some of their discussions kept confidential?

A Some matters discussed by the NAC are confidential. NAC members are expected to respect confidentiality and not to disclose information about sensitive subjects until clear and full permission has been granted by the Chair. Confidentiality enables NAC members to discuss and debate freely, and in some cases is necessary for financial or legal reasons. However, wherever

possible, the NAC seeks to be open with the beneficiary community. The quarterly newsletter and annual reports are two ways in which information is shared. Beneficiaries can also request to observe an NAC meeting by emailing feedback@tnac.org and will need to sign a confidentiality agreement.

Q I'm interested in standing for the NAC. What do I need to do?

A Observing an NAC meeting or talking to a current NAC member would help you find out more about what the role involves. Beneficiaries are alerted as an election approaches by the Trust staff and in the NAC newsletter. The process is explained afresh each year. You are required to advise the staff of your intention to stand for election and submit a manifesto by a certain date. Help and guidance is offered by a current member of the NAC, if requested.

Q How can I contact NAC members directly?

A You can email any member individually or ask the Trust staff to put you in touch by phone. Contact details are here: www.thalidomidetrust.org/about-us/our-people/nac. Alternatively, you can email feedback@tnac.org.