

## **GROUP GUIDANCE NOTES**

### **Mission statement**

To provide a NET Natter group that is designed to ensure that no patient (or their supporter) should ever have to walk the journey from diagnosis through treatment alone and without the support of other similarly diagnosed and locally based patients and supporters.

### **NET Natter group protocol**

1. NET Natter Groups are available to all NET patients, and their supporters, irrespective of race, ethnicity, sexual orientation, beliefs, religion or disability.
2. NET Natter meetings should be held in a public place, not an individual's home. Apart from Health & Safety reasons, this is to ensure all facilities required are available.
3. Disabled toilet and other access facilities should be available at every meeting.
4. Attendance at the group should be free of charge, except for parking or other travel expenses.
5. The length of the meeting can be variable, but as a guide 2-3 hours is a reasonable length of time. The format of the meeting (formal/informal) is to be agreed by the attendees - and may change over time reflecting the views and needs of the group.
6. NET Natter Groups are primarily for support - exchange of experiences, for information and education. They are not fundraising groups - however, groups may want to participate in fundraising activities - if so, please let the NPF know, so that the group can be supported in this.
7. Neither are the groups established for political means - the group shall not affiliate to any political group, pressure group or other association without the written permission of the NPF. If there are political concerns or an identified area where the group feels advocacy or lobbying may be required please contact the NPF to discuss how best to take this forward.
8. No individual medical advice should ever be given to any patient (or supporter) - unless adviser is qualified to do so. Volunteer organisers should encourage the sharing of experiences but should ensure that each person, and type of NET, is unique - and that all NETs should be considered and treated individually by trained NET specialists. Please contact the NPF with any concerns.

9. The volunteer organiser shall not invite any medical or pharmaceutical company to speak, present or distribute literature at any meeting.
10. The role of the volunteer organiser is to facilitate open discussion - to encourage all members to participate in discussions - to be able to speak freely, not to teach or instruct.
11. At every meeting, the volunteer organiser shall outline the current activities of the NPF and have available examples of NPF patient information books. The NPF will provide the volunteer organiser with a coordinator's pack, pop-up meeting banner, flyers, patient information, etc. . . if replacements or top-ups are required please contact the NPF.
12. The volunteer organiser will ensure the sign-in sheet is completed at each meeting, and that a welcome letter registration form is completed for all new members. This information is to be returned to the NPF via email or post within 10 days of each meeting.
13. The volunteer organiser shall not circulate any patient's details, including group email notifications (Bcc each member rather than general cc ), without first receiving the individual's written consent to do so. For healthcare professionals - adherence to professional code of conduct applies.
14. The NPF will reimburse all reasonable\* costs incurred by the group meeting organiser (see expense form). The organiser should ensure that all meeting costs are kept to a minimum (a maximum £100 inc refreshments). \*Venue, travel, advertising and {non-alcoholic} refreshments are costs the NPF will cover.
15. The volunteer organiser shall inform the NPF of all meetings - in advance - so that they can be advertised on the NPF website, NPF newsletter and can be fully supported. Notification to include venue (venue name, address and postcode), day and date - as well as time, and point of contact (with telephone number and / or email as preferred) - for confirmation.
16. The group shall inform the NPF National NET Natter Co-ordinator of any change in leadership / organiser of the group.
17. The volunteer organiser should not hold any personal information / documentation relating to the group or its individual members without written consent of the individual and/ or the NPF. Sign-in sheets and registration forms as previously stated should be sent to the NPF.
18. Should the volunteer organiser step down, they should notify the NPF as soon as possible - with name of successor if known. All NPF materials and any documentation relating to the group and/ or its individual members should be returned to the NPF.

*\*\*Volunteer organiser : the person(s) nominated to organise and chair the NET Natter Group. This person may be a NET patient, supporter and/or Health Care Professional.\*\**

**These notes are meant to offer guidance to ensure a safe and successful meeting.  
Please do not hesitate to contact the NPF nurse team with any questions you may  
have big or small: [nurses@netpatientfoundation.org](mailto:nurses@netpatientfoundation.org)**

