

Parent Support Group Action Pack



The role of a medical adviser in support groups

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Introduction

For support groups providing support for families and individuals with a specific condition or group of related conditions, a medical adviser can be of great value. The level of support they are able to provide to the group may vary, but the help they can offer may include:

- writing information on the condition for distribution by the group
- verifying information put together by the group
- being available to answer enquiries on specific aspects of the condition
- advising the group on new developments in treatment or research
- being available to speak to group members at annual events or family days.

Also, where a condition is very rare and almost all new diagnoses will go through one specialist, it can be very beneficial for all parties if the support group has a good working relationship with the specialist.

Finding a medical adviser

A group medical adviser will usually be a doctor who is a recognised expert on the condition you cover. This is likely to be a doctor at one of the centres of excellence, such as Royal Manchester Children's Hospital, Royal Hospital for Children in Glasgow or Great Ormond Street Hospital, London.

In the case of genetic disorders, an expert may be a geneticist at one of the UK Regional Genetics Centres. Sometimes a local paediatrician will become an expert on a specific disorder having become interested when involved in the care of a child.

You may also have become aware of the expert in your group's condition due to your own experience.

The importance of good quality information

Largely as a result of the internet, it is becoming increasingly easy to find information about specific and rare medical conditions. However, there is little monitoring of the quality of the information that is available online.

If your group decides it would like to provide some information about a condition to families, it is very important that this is of high quality and can be shown to be so. Enquirers approaching the group for information must be able to tell the source of the information, whether it is reliable and how up to date it is.

A medical adviser can write the medical information for the group, or if a member of the group who is not medically qualified writes information using suitable resources and references, the medical adviser could approve it.

How to ensure medical information meets quality criteria

All information you provide in paper format or on the group website needs to demonstrate that it is of the highest quality. Therefore it is important to list the following:

- the name of the medical expert who wrote it
- if written by the group, the name of the medical expert who approved it
- the qualification and job title of the medical expert
- the date when it was written.

An example is:

Medical text written January 2019 by Professor John Smith, Consultant Paediatric Neurologist, Any Town Hospital, Any Town, UK.

Or if the group wrote the material:

Medical text written January 2019 by Any Syndrome Support Group. Approved January 2010 by Professor John Smith, Consultant Paediatric Neurologist, Any Town Hospital, Any Town, UK.

You may wish to provide information on the latest research or other suitable resources available on the condition you cover. You will need to indicate where you got the information from by giving references and other validating information. A medical adviser may be able to help you select and approve the most appropriate information.

Using disclaimers

If you provide medical information, it is important to include a disclaimer such as:

Although great care has been taken in the compilation of this work to ensure accuracy, 'Any Syndrome' Support Group cannot accept responsibility for any errors or omissions. Any medical information is provided for education/ information purposes only. You should obtain further information from your medical practitioner.

If you include links to other websites, you should also have a further disclaimer:

Any links to external websites have been carefully selected but are provided without any endorsement of the content of those sites.