The role of a medical advisor

For groups providing support for families and individuals with a specific condition or group of related conditions, a medical advisor can be of great value. Not all will be able to provide exactly the same level of support, but the help they can offer to the group 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 the group members at annual events or family days.

In addition, 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 advisor

A group medical advisor 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 Sick 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 (a list of these appears on Contact a Family’s website). 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 have become aware of the expert in your group's condition due to your own experience. If you cannot identify an expert to be your medical advisor or would like further help with this, please contact the Rare Disorders Team at Contact a Family.

The importance of quality medical information and how the medical advisor can help

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

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 advisor can write the medical information for the group or if a member of the group writes information, using suitable resources and references, the medical advisor could approve it.

How to ensure that the medical information you provide 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 2010 by Professor John Smith, Consultant Paediatric Neurologist, Any Town Hospital, Any Town, UK

Or if the group wrote the material:

Medical text written January 2010 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. For this you will need to indicate where you got the information from by giving references and other validating information. A medical advisor may be able to help you select and approve the most appropriate information.

If you provide medical information, it is important to include a disclaimer like the example below:

*Although great care has been taken in the compilation and preparation 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 – you should obtain further information from your medical practitioner.*

If you feature 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.*

For more information about content on your website see the Group Action Pack guide Websites.

This guide is part of the Contact a Family Group Action Pack.
For more information please visit [www.cafamily.org.uk](http://www.cafamily.org.uk) or telephone 020 7608 8700.
Although great care has been taken in the compilation and preparation of this guide to ensure accuracy, Contact a Family cannot take any responsibility for any errors or omissions.
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