

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 role, but the help they might be able to offer 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

Additionally, 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 in the *Contact a Family Directory*). 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 such an expert to be your medical advisor or would like further help with this, the Rare Disorders Team at Contact a Family will be happy to help.

contact a family
for families with disabled children

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incorporating
The Lady Hoare Trust

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 which is becoming available.

If your group decides it would like to provide some information about the 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, its likely reliability and how up to date it is. To do this it will be very useful for the group to have a medical advisor.

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. You can achieve this by showing 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 last updated January 2004 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 knowledge available on the condition you cover. For this you will need to include references and other validating information. For all this, having a respected medical advisor is most important.

You will also need a disclaimer such as:

- *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.*

Further Help

These websites can give you further help on information quality issues. You may wish to discuss these with your medical advisor, board of trustees or Contact a Family.

http://www.judgehealth.org.uk/support_guidelines.htm advice on group websites.

<http://biome.ac.uk/guidelines/eval/summary.html> more to consider about medical information provided by your group.

<http://www.hiquality.org.uk> guidance on how to attain quality standards.

This guide is part of the Contact a Family Group Action Pack. For more information please visit www.cafamily.org.uk or telephone 020 7608 8700.

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