

Starting a national group



If you are reading this you have probably decided that you want to set up a support group for other families affected by the same condition as your child. This can seem a daunting prospect. Starting a group, on top of the demands of caring for a child with specific, often changing needs, takes up time and energy. This guide aims to equip you with the basic information on what setting up such a group can involve. It should help you through the most difficult first stages. Each group will be different so you may find some areas covered here are more relevant than others. The work involved in a national group becomes much easier once it has taken off and other parents are involved.

Know where you are going

One of the most important aspects of setting up a new group is to be clear about what you want to achieve through this. It may help to draw up a brief list of aims. This can clarify why the group is being set up and provides a base from which to develop. It also gives you a framework for deciding what needs to be done to move the group forward. Keep your aims short and simple.

Aims of the ** Syndrome Support Group***

To offer support to other families affected by ***** syndrome

To raise awareness of ***** syndrome with professional workers and other interested individuals

To raise awareness of the ***** Syndrome Support Group

Establishing ground rules

At this stage the group can take up more of your time than you had planned, and you need to be aware of this. Setting ground rules will help you to be realistic about how much time you can spend on the group and how it fits in with all the other demands on you. These could include:



209-211 City Road London EC1V 1JN

Tel 020 7608 8700 Fax 020 7608 8701 www.cafamily.org.uk info@cafamily.org.uk

Freephone Helpline 0808 808 3555 (Mon-Fri, 10am-4pm) Minicom 0808 808 3556

- attending to group work at times convenient to you
 - setting aside specific times when you can respond to enquiries
 - not allowing the group to become a full-time job
- not letting the group interfere with family life
 - using the answer phone at meal times and when you are spending time with the family
- not taking on individual family problems
 - telling families when you are not the best person to help
 - suggesting other sources of help where necessary
 - encouraging families to phone Contact a Family for specific information
- sharing tasks where possible
 - taking up offers of help even for the smallest tasks
 - not being afraid to ask for help
- stepping back if necessary
 - if family circumstances change, the group must take a lower priority

Spreading the word

Making contact with other families is a vitally important task for a national support group. Informing professional workers that your group exists can be a slow process. It is often also difficult to estimate how many other affected families there may be, especially if the condition is rare. Targeting the correct professional worker helps. Below are some ideas for spreading the word about your group, but remember that it may take a few attempts to get the message across.

- **Through the Contact a Family Helpline:** make sure the Helpline have full contact details for the group and keep them up to date with any changes.
- **Through other support groups:** depending on the condition the group is for, families may contact other organisations e.g. Mencap, National Society for Epilepsy. Make sure these organisations are able to refer families on to you.
- **Write a short article:** submit to *Share an Idea* (Contact a Family's magazine) and other group newsletters.
- **By letter:** draw up a standard letter which could be forwarded to families on your behalf through development centres or hospital departments (see example below).
- **Poster:** put together a simple poster for display. Ask parents who contact you to put one up in their development centre or hospital.
- **Through regional genetic centres:** write telling them about the group and asking them to pass on details to any newly diagnosed families.

- **Through doctors:** find out whether there are doctors specialising in your child's condition and send them details of the group.

Dealing with enquiries

The majority of enquiries will be by telephone, although some families may prefer to write or email. Professional workers often phone as the quickest way of obtaining information.

You may feel apprehensive about speaking to families on the phone who you have never met, but they are likely to be just as worried about ringing you! You will find that it becomes easier as you deal with more enquiries. The following guidelines may help, especially during the early stages.

- First impressions count - treat callers in a welcoming manner and put them at their ease.
- If it is inconvenient to speak when they call suggest an alternative time which is convenient for you both.
- Explain who you are at the beginning of the call and that you too are a parent of a child with the specific condition.
- Allow the caller time to tell their story - this may be the first time they have spoken to another family and they may be feeling apprehensive.
- Encourage the caller to go back to their doctor if they still do not have a definite diagnosis for their child.
- Avoid giving specific medical information and try not to get involved in specific enquiries about the treatment and management of a child - suggest the parent discuss their concerns with their doctor.
- If you are not able to help, say so and suggest other sources of help. Have contact details ready.
- If you are using an answer phone encourage callers to leave messages, call again or write to you if they prefer not to leave a message.
- If the caller is distressed allow them to talk and then arrange to call them back within a few days.
- Always encourage callers to keep in touch. Tell them about the group and how they can be involved. If possible, follow up calls with a short letter or information leaflet.
- Always maintain confidentiality when dealing with any enquiry.

The same guidelines can be applied when dealing with written enquiries. Try to answer letter from families as soon as possible. If you are receiving lots of requests for information from health information services, be selective; respond to those that you feel are the most appropriate.

You may also want to consider using a PO Box number for mail. There is a small charge for this, but it does allow you to keep your home address private.

Keeping in touch

Following the initial contact and sending further information, you may find that you do not hear from a parent again. There are various reasons why a family may choose not to keep in contact with you. They may feel it inappropriate to contact you unless they require further information. Or they may not realise what a national support group can offer them. You can encourage families to stay in touch by:

- following up the initial contact with a short, friendly letter
- sending a regular 'newsy' letter to families
- inviting families to write about their experiences for the group's newsletter
- asking parents to help in some way with the group
- offering them a link with another family in their area or in similar circumstances, if available

Sharing the load

When you first set up a group, it can seem easier to do everything yourself. This is best avoided. You will find the work becoming a burden and if there are other parents who want to contribute they will feel left out. There are positive benefits to involving other families in the running of the group:

- it strengthens ties between the families
- it gives others a sense of ownership and a stake in the group
- it allows you to develop initiatives
- decisions can be shared
- there is a wider pool of skills and experiences
- you can support each other

As you make contact with more families you will have the opportunity to encourage others to take on a more active role within the group. Some parents will be prepared to take on roles with a regular commitment, such as treasurer, secretary or newsletter editor. Others may prefer less formal jobs, such as fundraising or running a one-off event.

Any offers of help, no matter how small, should be taken up. Do not be afraid to ask for help. Use the group newsletter to encourage other parents to come forward and stress the positive benefits of being involved; your group is for all parents and you welcome their involvement.

Organising a meeting

The families you are in contact with will probably come from all over the country, making it difficult to organise meetings. However, some families who live near each other may wish to meet. Also the parents who take on the formal roles within the group will also need to meet occasionally to discuss the running and development of the group.

If you are organising a meeting you will need to take the following into account:

- look at where the families are coming from and then choose a central location which has good transport links
- a weekend is usually preferable for most families (subject to any religious observance)
- give plenty of notice
- avoid bank holiday weekends, school holidays and religious festivals
- allow time before and after the meeting to get to know each other

Do you need an honorary (unpaid) medical adviser?

You may wish to consider this, especially if you are planning an information leaflet. A medical adviser can review and validate any information you may wish to use and suggest ways of making it 'parent friendly'. Make sure you indicate clearly on your leaflets, website etc the name of your medical advisor and the date it was written.

Finding a sympathetic doctor with expert knowledge of the condition willing to take on this role may be easier than you think. Why not approach the doctor managing the treatment of your child? Write a letter on behalf of the group outlining how the group operates and requesting their involvement. Invite them to contact you for further details or to arrange a meeting to discuss what would be involved.

Gathering information

Some of the parents who contact you will be looking for information on their child's condition. In some instances they will have received very little written information from their doctor and may be looking to you to 'fill the gaps'. You may have some medical articles but think about whether these are appropriate to send to families.

If you do have access to a medical adviser ask for advice on the relevance of the material you hold. Also ask for advice on any new information which you want to send to families.

Fundraising

You should keep the costs involved in developing the group to a minimum. During the early stages the main costs will be postage, paper and photocopying. You should avoid personally financing the group or becoming out of pocket. Your group may be reluctant to ask for payment for sending out information, but there are alternatives:

- ask for a small voluntary donation to cover the cost of postage
- request professional workers to send a stamped addressed envelope for information
- ask for donations of stamps and envelopes
- keep telephone costs to a minimum by only phoning at off peak times and encouraging people to call you
- shop around for the best deals for photocopying
- ask your local Council for Voluntary Service if it can help with photocopying, stationery supplies etc.

You should keep receipts and a basic record of how much you spend. You may want to consider opening an account in the name of the group. Make enquiries with local banks and building societies about a simple savings account - a number of charity accounts are on offer but some do incur charges.

As you make contact with more families you may want to encourage some basic fundraising events. Money raised on this small scale can then be used to cover group expenses. For more information see the guide *Fundraising*, Contact a Family, Group Action Pack.

Dealing with the media

You may be tempted to use the media to 'spread the word' about your group. By getting into the press or on radio and television your group will be able to reach far more families.

However, before embarking on a media campaign think about the effects this might have on the families involved - are they prepared to put their child or family under the spotlight? Many groups are also concerned that the media can 'sensationalise' an issue or present negative images of a particular disability or condition.

If you are approached by the media for an interview, agree in advance on the questions to be covered. You may ask to see a copy of an interview or a story in advance of publication. But keep in mind that most journalists will feel that they should have editorial control over content. Making corrections of factual errors is one very good reason for seeing an advance copy; another reason is that you can alert group members before the article appears.

Encourage other families wishing to use the name of the group in the media to discuss the content of any article or interview with you beforehand. The guides on *Writing a press release* and *Speaking to the media*, Contact a Family, Group Action Pack, give further information.

Stepping back

Taking on the development of a national group, alongside the demands of caring for a child with additional needs or a specific condition, requires time and energy. It can be a positive, but exhausting experience.

There may come a time when you feel unable to continue your commitment. If this happens you need to step back from the group. You could take on a less demanding role, or stand down altogether. All parents involved in national groups should feel that they have this option and that their decision will be respected.

You should not feel that stepping back from the group prevents you from playing any part in the future. You may wish to take on a more active role at a later date when circumstances allow.

The role of Contact a Family

Contact a Family is on hand to give you support in setting up your group - and keeping it going. We can provide you with advice and assistance on all the issues raised in this guide.

For more information about the ways we can help please phone 020 7608 8700.

The Contact a Family Directory

The *Contact a Family Directory of Specific Conditions, Rare Disorders and UK Family Support Groups*, published annually since 1991, has become a well-known and widely used resource for professional workers. It contains comprehensive information on a wide range of conditions and includes the contact details of any appropriate support group.

Many groups find that inclusion in the Contact a Family Directory is an effective way of raising awareness and reaching other families. We are always happy to include newly established support groups.

Please phone 020 7608 8700 or email specific-cond@cafamily.org.uk for more information.

Example letter to parents

Date

***** Syndrome Support Group
123 Acacia Avenue
Any Town
West County ZS1 2WE
Tel. (0123) 456789

Dear Parent,

My name is Ann Smith and I am the parent of Jane who is affected by ***** Syndrome. For some time I have felt that there is a need for a Parents' Support Group for the families of children with ***** Syndrome. Your consultant at the Anytown General Hospital supports this initiative and has agreed to forward this letter to you.

The aim of the group would be to provide support and information to any family caring for a child with this syndrome. Most important of all, it aims to provide a sympathetic ear from someone who is the parent of a child with ***** Syndrome and therefore understands how other parents feel and what they are going through.

Your consultant is sending this letter to you on my behalf initially to provide confidentiality. If you feel you would like to know more about the group, please contact me. You can ring or write to me at the above address.

I look forward to hearing from you.

Yours sincerely

Ann Smith
National Contact

Example letter to professional workers

Date

**** Syndrome Support Group
123 Acacia Avenue
Any Town
West County ZS1 2WE
Tel. (0123) 456789

Dear Doctor,

The **** Syndrome Support Group has been formed to provide a meeting point for families of affected children.

The group aims to provide emotional support to families, information on the condition and an opportunity to meet other families of children with **** Syndrome.

We would very much like families to be informed of our existence so that they can decide whether they would like to make contact.

Please will you give any families known to you with a child with **** Syndrome the address and telephone number of the group.

If you require any further information about the group please contact me at the above address and I will be happy to answer your queries.

Yours sincerely

Ann Smith
National Contact

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

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