

Websites



Planning a website

A website is one of the most efficient ways of informing as many people as possible of the existence of your group and what it provides. Time spent in planning your first website or revamping an existing website is never wasted.

How do you begin?

- Look at the aims of your group and consider them anew. How might a website further these aims?
- Identify those to benefit from your website
- What information do you want to put on your website?

When you and your committee have re-confirmed the aims of your group, the people you want to reach and the information you wish to make available, there are a number of things you can do.

Content

Contact a Family's own website <http://www.cafamily.org.uk> has won a number of awards including Charity website of the Year (2000). Looking at Contact a Family's site will help you to identify components of a good website.

You will see that your website needs to contain:

- The contact details of your group and an email link
- The aims of your group
- A description of the disorder you cover written by, or checked and approved by, an expert on the disorder. Details of the medical authority should appear on the page or if you have a number of medical advisers you can put in a link to a separate page listing them
- Details of what your group offers to individuals and families
- If you are in touch with the doctor who identified the disorder you cover, ask him/her to write an introduction

contact a family

209-211 City Road London EC1V 1JN

Tel 020 7608 8700 Fax 020 7608 8701 Web www.cafamily.org.uk e-mail info@cafamily.org.uk
Helpline 0808 808 3555 or Textphone 0808 808 3556 Freephone for parents and families

Other items might include:

- Links to reputable sites containing relevant information such as universities, medical sites, online text books and organisations useful to your members such as Contact a Family and other advice agencies
- A publications list including links to full text versions of your leaflets
- Copies of your newsletters
- History of your group
- Well known patrons
- Details of research into your disorder
- Reference material on your disorder
- A forthcoming events or 'what's new' section
- Stories from families or members of your group

Research

Many groups have already developed excellent websites: have a look at many as you can. This will give you an idea of what your own site might contain. There are links from many of the entries in the online Contact a Family Directory to groups' websites. Some of them are:

- <http://www.climb.org.uk> CLIMB (supports families whose children have metabolic disorders)
- <http://www.jtsma.org.uk> Jennifer Trust for Spinal Muscular Atrophy
- <http://www.rarechromo.org> Unique – the Rare Chromosome Support Group
- <http://www.encephalitis.info> Encephalitis Support Group

Setting up or revamping a website

Looking for advice:

- Look at the approval claimed for individual web sites you come across. This is usually signified by an icon providing a live link to the website maintained by the evaluating organisation. For example,



- Many of these links show either a list of rated sites or, more usefully, details of how they rate the site. This information can be very useful in looking at your own existing or planned website.

Much of the advice listed below relates to medical information but the principles have a much wider application:

- <http://www.judgehealth.org.uk> JUDGE – Web Sites for Health: Support Group Guidelines joint project of University of Northumbria and Contact a Family
- <http://www.hiquality.org.uk> Guidelines on Health Information Quality from the Centre for Health Information Quality (CHIQ)
- <http://www.usability.gov/guidelines> Guidelines for websites from the US National Cancer Institute
- <http://www.rnib.org.uk/digital/hints.htm> Advice from the Royal National Institute for the Blind (used to achieve effective websites generally)
- <http://biome.ac.uk/guidelines/eval/howto.html> BIOME Evaluation Guidelines (formerly Omni guidelines) used by NHS Direct Online

As your website will include information about medical disorders, looking at further advice on the content of medical information websites will be helpful.

Web space

Most internet providers (including those offering free access to the Internet) also provide free website space in their packages. Both Netscape and Internet Explorer have helpful web facilities in their programmes together with tutorials and templates. Some of these are very good and will cover your needs for a considerable time. Some Internet Service Providers (ISPs) such as *Virgin Net* provide free space when you register for emails. Check with a knowledgeable friend or group member to find what your own software contains.

Web design

Some groups have found that a member, or member's relation or friend, will turn out to be either a computer professional or enthusiastic and skilful amateur. Take advantage of this - some excellent sites have resulted from group's skill surveys. Of course, you can go to an expert commercial provider but they are expensive and may not necessarily produce a better result than your group can.

Some specific condition networks have started out with simple pages appearing within company websites where a supporter is an employee. This allows the group to gain experience of what information their site should hold and does not cost anything. However, at a later date the group may want to have its own distinctive website address and you will then need to check that links to your site are updated accordingly.

Link from your site to the online Contact a Family Directory. Contact a Family will put a link from your entry in the Contact a Family Directory to your website. When your site is up and running you should register it with the major Internet search engines. Advice on this can be found at <http://www.promotionworld.com>. You should also publicise the existence of your site on your letterhead, publications and in your email signature.

How do you ensure that search engines find your site?

To find information on the Internet, you use search engines.

- Search engines are a little like the computer system at your local library, but they are much more powerful.
- A library computer usually finds books by title and author but search engines employ a number of methods to identify the correct sites that people are looking for.
- Search engines vary in the way they work; some look at the title of a file, some look at the first paragraph of information, others scan the whole content.
- Some search engines search a file on the website accessible to the search engine but hidden from the Internet user. This file can contain up to 500 key words to your site. For example if your group covers a syndrome which is characterised by heart and kidney anomalies with some affected people having visual impairment and others have a learning disability, the hidden file might contain the following words: Disability, anomaly, heart, cardiac, kidney, renal, visual, impairment, learning, etc. Include any word that might possibly feature in a search by someone looking for you.

Accuracy and currency

It goes without saying that the information you carry on your website must be accurate and up to date. However, like all people involved with the running of a voluntary support group you will be very busy and time goes by very quickly. Diarise the checking of your website at least every 2 or 3 months. There should be an indication of when the site was last updated on the home page. Where you carry the description of the disorder you cover details of the date the text was written, who wrote it, their qualifications to write it and where they are located must be carried. Contact a Family does this in the following way:

Medical text last updated January 2003 by Professor Dian Donnai, Consultant Clinical Geneticist, St Mary's Hospital, Manchester, UK.

Naming your website

Having your own domain name such as **www.smithsyndrome.org.uk** is something to aim for. The problem for most people is the cost involved in having your own domain name and the technicalities of getting one.

Most groups opt for a **.org.uk** domain (the use of the word **.org** denotes a charitable or not-for-profit organisations) but some choose the more global **.org** or **.com**. Once you have registered the address it is yours for as long as you pay the annual fee. You can move the site to a different ISP whilst keeping the same address.

Have a look at Nominet.uk **http://www.nominet.org.uk** which gives clear information about domain names. Nominet is officially recognised as the **.uk** domain name registry by the internet industry, users and the UK Government. Nominet ensures that each domain is only used once and all the other providers have to register through them.

There are a number of providers of domain names offering varying services:

<http://www.123-reg.co.uk>

- simple to register
- competitive pricing
- no charge to transfer the domain away from them if you wish

<http://www.freenetname.co.uk>

- free ISP
- free domain name, no annual fee
- one-off fee of about £95 to move away from Freenetname
- relatively easy and quick to set up the account
- only offers .co.uk and .org.uk
- Online Q & A support

<http://www.domainnameshop.co.uk>

- competitive pricing
- wide range of domain names
- free phone support

Community Website Builder

The Community Website Builder allows registered UK charities, non-profit making organisations and volunteer led groups or organisations to build and maintain their own website free of charge. To qualify for use of the free service your organisation must be from the United Kingdom, providing a clear benefit to the local community, and be one of the following:

- registered charity
- non-profit making organisation
- volunteer led group / organisation

If you are unsure if your organisation qualifies or you are an international / non UK organisation, you can check your eligibility by sending full details of your organisation and its intended use of the website to e-mail: **support@ik.com** or Tel: 08700 112850. To start using the Community Website Builder go to **<http://www.communitykit.ik.com>**.

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.

Copying of the material within this guide is permitted. Please include a credit to Contact a Family.

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