ECTODERMAL DYSPLASIA SOCIETY
LOOKING FORWARD: THE NEXT 3 YEARS
FINAL REPORT & ACTION PLAN
Author: David Wyatt (Chairman)

Introduction
At our Executive Committee meeting in January 2003, it was decided that we should look at the future development of the Society following our first AGM. This process began at the next Executive Committee Meeting in May 2003 when a fairly brief discussion occurred partly centered around the mission statement and aims/objectives included below:

EDS Strap line: “supporting a normal lifestyle”

EDS Mission Statement: “Our mission is to provide information, advice and support to those affected by Ectodermal Dysplasia”

Aims/Objectives:
“The Ectodermal Dysplasia Society will promote the health of persons affected by Ectodermal Dysplasia and any related condition and help support their families and carers.”

We will do this by

1. the advancement of the education of the medical profession and the general public into Ectodermal Dysplasia and its implications for the family
2. the promotion of research into the causes, effects, treatment and management of Ectodermal Dysplasia and to disseminate the useful results thereof
3. the liaison with professionals on the Society’s Medical Advisory Board
4. the creation of a positive supportive network of parents, individuals, families and professionals in order to share ideas, experiences and give emotional support
5. the support of families and individuals in their right to be kept informed about the likely progression of Ectodermal Dysplasia and more importantly of the outcome of treatments offered at various stages
6. the support of persons with Ectodermal Dysplasia in all their negotiations for financial aid and other services
7. the liaison and sharing of information with other national and international groups linked with Ectodermal Dysplasia
8. the production, reproduction and circulation of newsletters, papers, etc, in order to keep people informed
9. the maintenance of a website and dissemination of information to make known the work and existence of the Ectodermal Dysplasia Society
10. the promotion and support of all activities leading to an improved quality of life

It was decided that the way forward was to examine each of these ten aims/objectives in turn aiming to identify: (1) how we were currently meeting them; (2) some future possibilities. Members of the committee were invited to submit contributions to the Chairman who would write a paper on the future strategy.

Following contributions, it was decided to structure this paper in the following way. Firstly, each of the ten aims/objectives are discussed in turn in two sections; (1) current position; (2) future possibilities. Secondly,
resource, both human and financial, implications are considered. Finally, a number of possible developments are outlined and the resource implications detailed.

Following discussion of Draft 1 at the Executive Committee Meeting of 27/9/03, the Chairman further revised the paper. Draft 2 was then circulated to the Committee members who were asked to respond with any further suggestions by mid December which resulted in Draft 3 which was considered by the Committee at their January meeting. Draft 3 was also set to members of MAB who produced a detailed joint response. The fourth and final draft which in particular incorporated the views of MAB was discussed at the Executive Committee Meeting on 8/5/04. This resulted in agreement of this final report and action plan.

ANALYSIS OF THE TEN AIMS/OBJECTIVES

1. the advancement of the education of the medical profession and the general public into Ectodermal Dysplasia and its implications for the family

Current Position

In discussing this aim, we need to distinguish between the education of the medical profession and that of the general public. As regards the medical profession, we need to consider both hospital consultants and general practitioners remembering of course to include dentists, health visitors and nurses. As regards consultants these would seem to fall into three categories: it is helpful to consider three types: (1) those who have never heard of ED; (2) those who know about ED but are unaware of how it affects family life; (3) those who are unaware of patient organisations such as ours and what they are doing (DP). These categories would also apply to general practitioners and dentists. We are currently targeting those in the first category in collaboration with the MAB via journals. As regards the second group, we are beginning to do this by giving presentations and attending conferences primarily aimed at dental professionals. The third category will hopefully find us through the internet and various directories and health databases in which we are listed (DP).

As regards the general public we need to ascertain who we are trying to reach. The following groups of people could be considered important targets: education departments (impact of ED in schools); social services (air conditioning), parents of new born babies (to warn of potential risks of over-heating); those with ED who are unaware of support groups such as ours. Some groups, such as schools and social services, are contacted as someone with ED goes to school or first requires air conditioning; others need alerting to either ED and/or our existence. People with ED are becoming aware of our existence through articles in national publications and through our website. We are not at present targeting the important group of parents of new born babies. We already have access to a journalist who has placed feature articles in magazines such as “Woman”.

It is estimated that there are probably 800-1000 people with ED in the UK of which we know of approximately 250.

Future Possibilities

(1) Collaborate with other interested parties such as SIDS Foundation to promote an awareness of infant overheating among midwives and health visitors. ¹
(2) MAB to produce a paper on the dangers of overheating in infancy (including sweat test) for submission to a paediatric journal. ²
(3) Join forces with GIG and negotiate a regular Patient/Family Support Group slot in the BMJ. ²
(4) Set up a regular e-mail updates service for professionals circulating titles and abstracts of scientific publications on ED and related themes ²
(5) Dental members of MAB to produce a collaborative paper on ED for publication in the British Dental Journal. ³
(6) Produce a list of journals, magazines and newspapers who might be interested in aspects of ED with the aim of writing to them offering to produce customised articles.
(7) Gather information from members about the quality of service they have received from the NHS and pass on these comments to the relevant NHS Trust. ⁴
(8) Investigate the targeting of the nursing profession through the use of nursing journals (Nursing Times, Nursing Standard and the free publication RCN) and study days/course.
Notes

1 Originally the aim was to target all parents of new born babies through ante- and post-natal medical services. However, MAB expressed the following views: “Targeting the parents of all newborn infants, providing information about ED during pregnancy and soon after delivery, would be difficult. The incidence of ED is so low that it will be hard to persuade midwifery and health visitor or community paediatric services that this group of conditions needs to be mentioned specifically to the parents of every infant in the UK. Instead, it might be possible to look at the advice given to parents by midwives and health visitors about keeping babies warm. This could be done locally, through each community midwifery and health visiting team and each training school. There are other potential reasons for concern about the overheating of infants, and the EDS might be better advised to make common cause with other interested parties in terms of promoting the general awareness that infants can overheat – such as the Sudden Infant Death Foundation and any groups involved with the long-term consequences of infection in infancy.”

2 Originally the suggestions was for MAB to produce a collaborative paper on ED for publication in widelyread journals such as “the Lancet” “British Medical Journal” and “Nursing Journal” to target in particular GP’s, Health Visitors and Nurses. However, MAB produced the following detailed response which led to (3), (4) and (5): “A paper aimed a high profile journal, such as BMJ or Lancet, would need to have a very clear message and contain some really novel research finding or evidence-based recommendation. Simply putting together a reminder for professionals based on research findings from the last half century would not be sufficient”

“ An alternative approach would be to talk with Alistair Kent of GIG about negotiating a regular Patient/Family Support Group slot with the BMJ (or similar). If it’s the idea of the EDS, then the EDS could have the first shot, but we doubt if a solo approach to the BMJ would work. GIG would probably need to join in with similar groups supporting patients with non-genetic problems, but at least GIG would have some clout. This idea udl be worth thinking through with GIG, the Patients’ Association and perhaps the Consumers’ Association (Health Which).”

“A short piece about ED and the dangers of overheating in infancy or when performing a sweat test (to check out the possibility of cystic fibrosis in a child with failure to thrive and chest infections, as can occur in XHED) could be more readily submitted to a paediatric journal and might be a better goal for the immediate future.”

“In addition to the above initiatives, we wonder if the EDS could circulate the titles and abstracts of any publications or spoken conference papers on ED and related themes to any interested professional (or anyone else for that matter). This would entail having a regular search on a few key words (especially ‘ectodermal dysplasia’) through PubMed, Medline etc. and distributing this through e-mail to those who sign up. The Rett Syndrome Research Foundation does this and a lot of professionals receive these updates regularly (every week or two). This service could be offered free to anyone interested, and would provide an opportunity to circulate professional bodies (British Society for Human Genetics and comparable societies for dermatology, ophthalmology, dental practitioners, paediatricians etc.) This in itself would keep the relevant professionals interested and updated.”

3 MAB commented: “the approach you suggested for the BMJ might well work better for the British Dental Journal – but the dental members of MAB had better think about this.”

4 MAB commented: “There is an increasing need for service providers to involve users in the evaluation of their services and in setting appropriate targets for the services to reach – in terms of the quality of the service provided and the experience of the users in the care pathway. The EDS could gather information from its members collecting examples of both good practice (that could be adopted more widely) and of problems (to be avoided when targets are set). These positive and negative examples could feed through NHS Trusts to guide the development of services in the future. The Eastman conference next year is clearly a good example of this process in operation – in genetics, ophthalmology and dermatology we are further behind, but could still benefit from the experiences (good and bad) of your members.”
2. the promotion of research into the causes, effects, treatment and management of Ectodermal Dysplasia and to disseminate the useful results thereof

Current Position

We disseminate the results of research through publishing articles written by members of MAB for the newsletter. Our 2003 Conference included several presentations from medical professionals (mainly members of MAB). We are assisting in a couple of projects by allowing researchers access to some of our members. The setting up of the MAB has drawn professionals together and given them an opportunity to network and share ideas which should lead to more research into ED.

Future Possibilities

(1) Conduct an audit, with the help of the MAB of what research worldwide is being carried out at present.
(2) More information in our newsletters regarding research that is being carried out.
(3) Raise the profile of British research possibly through the collaborative article discussed under Aim 1.
(4) Raise members awareness of the need for non-genetics based research via the newsletter (including sounding out the membership regarding issues which need addressing. 5
(5) Support research financially by making grants although this would have major resource implications.

Notes

5 MAB comments: “Yes, indeed. While genetic research is required to determine the underlying causes of the various different types of ED, it is important to acknowledge that such understanding may well take many years to translate into direct benefit for affected individuals – and the opportunities for helpful intervention through this genetic knowledge may well be very limited indeed. Other types of research may be needed to address the issues that affected individuals and their families encounter every day – including research into physiology (regulation of temperature) and clinical psychology (behaviour problems). These more applied clinical research areas can be perhaps tackled with fewer resources than basic science research and the EDS should continue to sound out its membership to find out the practical issues where applied research could be of benefit to families.”

3. the liaison with professionals on the Society’s Medical Advisory Board

Current Position

This is achieved through twice-yearly meeting of MAB (a pool of highly qualified professionals covering a range of ED-related fields) at which Diana Perry and Sue Atkins are present. As a result of these meetings and other liaison directly between Diana Perry and members of MAB, members of MAB are available to: (1) write articles; (2) attend conferences and give presentations; (3) recommend consultants who have an understanding and/or experience of ED throughout the UK; (4) offer advice, support and information; (5) write to journals.

Whilst some would see us adequately fulfilling this aim, others would question whether we are getting the best out of them and it certainly seems strange that we are carrying out this review process without involving them; as one trustee says: “do we know where they see things going?”.

Future Possibilities

(1) Diana Perry with the MAB to produce individual factsheets about the different ED syndromes. 6
(2) Contact the producers of software (such as EMIS) for GPs which contains information about support groups and conditions.

Notes

6 MAB comments: “The preparation of factsheets about the various types of ED is indeed a good idea, with the benefit of highlighting those areas where further research is needed as well as the provision of accessible information to those who need it. The principal drawback is the time it would take to compile the information and to prepare the leaflets. Could this be done jointly with the NFED?”
4. the creation of a positive supportive network of parents, individuals, families and professionals in order to share ideas, experiences and give emotional support

Current Position

We have details of all our contacts and members, and Diana does try and put people in touch with each other when requested. Much of the support is provided by Diana herself and there will come a time when Diana can’t support all the members on a individual basis and some way of trying to encourage them into smaller self-help groups or to have other people who can talk to members might be helpful.

Future Possibilities

(1) Create a ‘map’ of ‘whose in touch with who’.
(2) Identify people who can also offer direct support to people.
(3) Create a network of regional self-help groups.
(4) Set up the database to facilitate the above.
(5) Aim to devolve support by either appointing experts in particular fields such as air conditioning or grant applications or by having regional co-ordinators who cover all aspects of support.
(6) Locate more people wishing to get involved who are willing to give advice to new members.
(7) Diana and Sue to do “on tour” contacting local representatives and arranging meetings to discuss with them the setting up of local smaller support groups.

Notes

7 MAB comments: “The old idea of holding a regional meeting each year in a different place, in lieu of a centralised national meeting, would also help to firm up and promote local contacts between individuals.”

5. the support of families and individuals in their right to be kept informed about the likely progression of Ectodermal Dysplasia and more importantly the outcome of treatments offered at various stages

Current Position

This would appear to be an area that we are not addressing at the moment.

Future Possibilities

(1) Discuss with the MAB how we can address this issue.

Notes

8 MAB comments: “We are not entirely clear what you have in mind here. The MAB is clearly not able to comment on the progression of disease or the outcome of treatment in individual cases. If you are referring to new information emerging about ED (or at least specific types of ED) from research, then this should be accessible to MAB – and the EDS more generally – through the usual means of published literature and/or the internet. The MAB and the Trustees could certainly keep a watching brief on new research findings and jointly prepare short updates for EDLines.”

6. the support of persons with Ectodermal Dysplasia in all their negotiations for financial aid and other services

Current Position

As regards financial benefits we support members as follows: (1) informing members of DLA, CA, etc.; (2) offering to complete forms; (3) offering to help in appeal situations by providing written information.
We also have produced information packs to help families with ED contact schools regarding the special needs of an ED child. Additionally, we have extensive experience on dealing with Social Services regarding air conditioning.

**Future Possibilities**

1. Extend this aim by giving financial support to members in need for items such as air conditioning or cooling jackets. Support might also be given for attending ED conferences.
2. Raise money specifically for a Support Fund for which we would invite applications.

   With respect to this one trustee comments: “I am very concerned if we try to raise funds and then issue grants directly to people for medical work. I feel that we should be encouraging members to find their own way of funding things with reference to trust or grant making authorities, etc.”.

3. Produce a Questions and Answer sheet to send to members requiring help with completing DLA forms etc.

**7. the liaison and sharing of information with other national and international groups linked with Ectodermal Dysplasia**

**Current Position**

We have made contact with all the ED and IP organisations and support groups that we are aware of with one exception (ED Mailing List). At present we: (1) send our newsletter to them; (2) we have their addresses in our new members pack; (3) we link to their websites (or have contact details on our website). In the past we did link to the Mailing List but took the decision to only link to official groups which both made an attempt to only present accurate information and adopted a positive approach.

**Future Possibilities**

1. Communicate better with other groups and find out what they are doing in their own country as communication tends to be mainly one way (us to them) at the moment.

**8. the production, reproduction and circulation of newsletters, papers, etc, in order to keep people informed**

**Current Position**

We currently produce four newsletters a year. These are produced using Word and while mainly text and non-glossy have a professional appearance. The format is folded A3, double-sided, with additional A4 pages inserted if necessary. The final A4 leaflet makes good use of columns and other presentation features. Moving to a more glossy format has been discussed in the past but rejected as the current format is “fit for purpose”.

However, others see room for improvement: “I believe the newsletter could be improved greatly and we have more than enough content to increase the number of editions; we could email it to people in colour and use digital photographs and by improving the quality we might increase the amount that people are prepared to pay for it”.

**Future Possibilities**

1. Make more use of photographs in the newsletter.
2. Increase the number of newsletters to 6 per year.
9. The maintenance of a website and dissemination of information to make known the work and existence of the Ectodermal Dysplasia Society

Current Position

The Society owns two main domains: www.ectodermal dysplasia.org (ED site) and www.incontinentia-pigmenti.org (IP site). The ED site has been running since August 2000 with the IP site introduced in October 2002. We also own the closely related “.com” domains and have set up webforwarding on these so that surfers are automatically redirected to the “.org”. Both sites are maintained by David Wyatt with the majority of work being done in school holidays (major work is usually undertaken during the long summer holiday). Support, mainly technical advice, is also given by Daniel Brotchie who works with Colin Willoughby (one of our MAB) at Liverpool. For the record the purchasing details are included below:

- We purchased www.incontinentia-pigmenti.org and ip.com domains via Daniel Brotchie from Host Europe for £52 p.a. (bought late September 2002 and registered to Diana Perry on behalf of the Society; I presume that we have paid for two years)
- Daniel has set up web forwarding on the ip.com site so that anyone typing in ip.com is automatically redirected to the ip.org site
- Daniel repurchased ed.com and set up web forwarding to ed.org (bought in late October 2002 using our EDS account with Host Europe; done for two years at a cost of £22).
- For the record, David renewed our registration with UK2.NET of ed.org in mid September 2002 for 2 years for £180 approx. We paid over the odds as we have very similar facilities at Host Europe for ip.org for around £41 p.a. The ed.org site is registered to David Wyatt on behalf of the Society.
- Currently, we pay around £150 p.a. for our various web sites.

The ED site has two versions: (1) “Frames” - which uses both frames and cascading style sheets; (2) “Text-Only” - which is kept deliberately simple for visually impaired surfers and those with older browsers. Both versions are written in the latest version of HTML (XHTML1.0) and all pages are validated using a free service on the internet.

The “Frames” version has a simple but clean and professional look. This approach speeds up downloading as well as making it easier to produce and maintain. The recent introduction of cascading style sheets will allow us to trial a variety of new “looks”.

The ED site contains the following information: information on ED from our leaflet; details of what the Society does and how to contact us; regular “News” items; over 30 articles, divided into “Medical & Scientific” and “Personal”, taken mainly from past newsletters; links to other ED and IP sites.

The IP site has a single page which contains some basic information but the prime aim is to link people to our ED site which makes use of an IP icon to direct people to an IP ‘index’ page on the ED site which links to various articles and includes contact details of all IP support groups.

We are able to obtain detailed statistics from our hosting service for both the sites. Currently the ED site has around 4000 visits per month but the IP site only 50-70 visits. This difference may reflect the lower ranking (usually lower than 20th) of the IP site. By contrast the ED site is almost always ranked in the top 5 and also appears in a number of directories which increasingly have ED and, to a lesser extent, IP sections.

Future Possibilities

1. Improve the visual appeal of the “Frames” version by using different fonts and colours (the colours will change from maroon and green to yellow and blue with the forthcoming introduction of the new logo).
2. Undertake a major redesign by changing from frames to tables to control layout.
3. Improve the content of the ED site which has been mentioned by two committee members. Suggestions include: (a) a page aimed at the medical/scientific community; (b) a few pictures of the general look of an ED person, teeth, eyes, etc.; (c) more articles which include visual information as only Colin Willoughby’s article on eye problems does this at present; (d) highlight the topics covered in our articles by including either short summaries or an index (e) more information on how ED may affect individuals to reduce number of people contacting Diana.
Another committee member makes the following comment: “Perhaps it seems to me that information and communication is the key to the future and we should continue to seek ways that we can educate professionals and members. In my view this is where the website will become increasingly important. The more information that is available on the web means the fewer people that need to be spoken to at length.”. A counter argument could be this might discourage people making direct contact with the Society probably to their detriment.

Returning to Aim 9, the website certainly makes known the existence of the Society as many new contacts, from all over the world, come from initially finding our website. It is in the area of dissemination of information that we are less successful.

10. the promotion and support of all activities leading to an improved quality of life

Current Position

In many ways this aim encompasses all the others. Diana writes as follows: “Improving the quality of life is done by informing members of the day to day management of ED, help in informing schools of ED, etc., but I feel we could do a lot better. Apart from newsletter articles giving information, I can only help with management if people ask questions and very often they don’t; largely because they feel their question sounds silly when in fact the problem is usually typical of ED. Very often questions come out when I chat on the phone to people. Maybe more phone communication should be done on a regular basis?”. This is mentioned below as are other suggestions that do not seem to fit naturally under any of the other aims.

Future Possibilities

(1) More phone communication on a regular basis.
(2) Ensure that new members without a computer receive copies of articles in the back issues of the newsletter.
(3) Produce a FAQ sheet for the New Members Pack.

RESOURCES

Currently these are as follows (free of charge unless stated otherwise):

♦ Office facilities provided at 108 Charlton Lane.
♦ Diana Perry works as Executive Officer (Family Liaison) for approximately 25 hours per week.
♦ Mary Rawson was employed as an Administrator for 15 hours per week (annual salary is £4900 approx). Mary has recently been replaced as Administrator by Sue Atkins (annual salary is £5800 approx)
♦ David Wyatt (teacher of biology and some IT) spends on average 2 hours per week as Webmaster and Chairman.
♦ Martin Greenwood (financial background) acts as Treasurer.
♦ Mandy White has been dealing with matters relating to air conditioning and has gained considerable experience and expertise. She also has experience in the nursing context of the Criminal Records Bureau.
♦ Ian Perry (business background), John Moss (general practitioner), Andrew Lea and Sarah Crosby are other trustees who contribute their knowledge and experience to the Executive Committee.
♦ Of the trustees and employees, only Sue, Martin and John have no direct experience of ED in their family but all know the Perry family.
♦ To keep the Society running at its current level requires an annual income of £10000.
♦ The Executive Committee have decided that £3000 should be held in reserve as working capital/contingency fund.

It is important to realise that our resources are quite limited; as one trustee writes: “the resources we have are already stretched; the administration occupies Sue for the hours that she is working, and Diana is constantly embroiled in family support”.

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POSSIBLE FUTURE DEVELOPMENTS

These have been divided into four categories: (1) easy, cheap; (2) easy, expensive; (3) difficult, cheap; (4) difficult, expensive. As a rough guide, “easy” = less than 35 hours; “cheap” = less than £250. However, it should be noted that where the time is to be used by Diana and/or Sue in the office, rather than by other volunteers, the cost has been worked out based on the salary paid to Sue making some “easy” tasks “expensive” (any tasks requiring more than 20 hours of office time).

Listed in the table below are all possibilities mentioned in the analysis together with their resource implications and category (1= easy/cheap; 2= easy/expensive; 3= difficult/cheap; 4= difficult/expensive).

<table>
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<tbody>
<tr>
<td>1/8</td>
<td>Gather information from members about the quality of service received from the NHS and pass on these comments to the relevant NHS Trust.</td>
<td>Time (15 hrs DP/SA)</td>
<td>1</td>
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<tr>
<td>1/9</td>
<td>Investigate the targeting of the nursing profession through the use of nursing journals and study days/courses.</td>
<td>Initial investigation would involve writing a few letters (10 hrs DP/SA).</td>
<td>1</td>
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<tr>
<td>2/2</td>
<td>More information in our newsletter regarding research that is being carried out.</td>
<td>Time (2 hrs per newsletter DP)</td>
<td>1</td>
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<tr>
<td>2/4</td>
<td>Raise members awareness of the need for non-genetics based research via the newsletter.</td>
<td>Time (1hr DP)</td>
<td>1</td>
</tr>
<tr>
<td>3/2</td>
<td>Contact the producers of software (such as EMIS) for GPs which contains information about support groups and conditions</td>
<td>Time (5 hrs JM/DP)</td>
<td>1</td>
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<tr>
<td>4/1</td>
<td>Create a ‘map’ of ‘whose in touch with who’.</td>
<td>Time (8 hrs DP/SA)</td>
<td>1</td>
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<tr>
<td>4/2</td>
<td>Identify people who can also offer direct support to people.</td>
<td>Cost of mailshot (£10) Time (15 hrs DP/SA)</td>
<td>1</td>
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<tr>
<td>4/6</td>
<td>Locate more people wishing to get involved in giving advice to new members</td>
<td>Linked with 4/2 and would mainly involve following up mailshot with phonecalls (15 hrs DP/SA)</td>
<td>1</td>
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<tr>
<td>5/1</td>
<td>Discuss with the MAB how we can address the issue of treatment/management</td>
<td>Time (10hrs DP/MAB)</td>
<td>1</td>
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<tr>
<td>8/1</td>
<td>Make more use of photographs in the newsletter.</td>
<td>Time (2hrs per newsletter SA)</td>
<td>1</td>
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<td>9/1</td>
<td>Improve the visual appeal of the “Frames” version by using different fonts and colours(the colours will change from maroon and green to yellow and blue with the forthcoming introduction of the new logo).</td>
<td>Time (20hrs DW)</td>
<td>1</td>
</tr>
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<td>9/3</td>
<td>Improve the content of the ED website Suggestions include:(a) a page aimed at the medical/scientific community; (b) a few pictures of the general look of an ED person, teeth, eyes, etc.; (c) highlight the topics covered in our articles by including either short summaries or an index</td>
<td>Time (a- 5 hrs DP/DW; b- 10 hrs DP/DW c- 25 hrs DW)</td>
<td>1</td>
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<tr>
<td>10/2</td>
<td>Ensure that new members without a computer receive copies of articles in the back issues of the newsletter.</td>
<td>Variable depending on need but £10 for copying and postage plus time (2hrs SA)</td>
<td>1</td>
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<td>10/3</td>
<td>Produce a FAQ sheet for the New Members Pack</td>
<td>Time (10 hrs DP)</td>
<td>1</td>
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<td>1/1</td>
<td>Attend conferences other than just those in the dental field.</td>
<td>Conference fees, travel, subsistence (£250 per conference) plus time (20 hrs DP)</td>
<td>2</td>
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<tr>
<td>1/4</td>
<td>Join forces with GIG to negotiate a regular Patient/Family Support Group slot in the BMJ and if successful produce an article.</td>
<td>Liaison and negotiation (£20, 10hrs); article (20 hrs DP)</td>
<td>2</td>
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<td>No.</td>
<td>Task Description</td>
<td>Cost/Time</td>
<td>Duration</td>
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<tr>
<td>1/5</td>
<td>Set up a regular e-mail updates service for professionals circulating titles and</td>
<td>Minimal costs apart from time; initial setting up and advertising (30 hrs);</td>
<td>2</td>
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<td></td>
<td>abstracts of scientific publications on ED and related themes.</td>
<td>if done every month it would require around 35 hrs p.a. (likely to be done</td>
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<td>by SA as regular commitment needed)</td>
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<tr>
<td>1/7</td>
<td>Produce a list of journals, magazines and newspapers who might be interested in</td>
<td>Time (25 hrs DP/SA) for initial research and letters</td>
<td>2</td>
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<td>aspects of ED with the aim of writing to them offering to produce customised</td>
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<td>articles.</td>
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<td>6/3</td>
<td>Production of a Q&amp;A sheet on filling in forms etc.</td>
<td>Time (25 hrs DP/SA)</td>
<td>2</td>
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<tr>
<td>7/1</td>
<td>Communicate better with other groups and find out what they are doing in their</td>
<td>Time (20 hrs DP/SA)</td>
<td>2</td>
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<td></td>
<td>own country.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1/3</td>
<td>MAB to produce a paper on the dangers of overheating in infancy for submission</td>
<td>Time (100 hrs MAB)</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>to a paediatric journal.</td>
<td></td>
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<tr>
<td>1/6</td>
<td>Dental members of MAB to produce a collaborative article on ED for publication in</td>
<td>Time (100 hrs MAB)</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>the British Dental Journal.</td>
<td></td>
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</tr>
<tr>
<td>2/1</td>
<td>Conduct an audit, with the help of the MAB of what research worldwide is being</td>
<td>Time (100 hrs MAB/DP)</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>carried out at present.</td>
<td></td>
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</tr>
<tr>
<td>2/3</td>
<td>Raise the profile of British research possibly through the collaborative article</td>
<td>None (see 1/6)</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>discussed under Aim 1.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>9/2</td>
<td>Undertake a major redesign by changing from frames to tables to control layout.</td>
<td>Time (100hrs DW)</td>
<td>3</td>
</tr>
<tr>
<td>10/1</td>
<td>More phone communication on a regular basis.</td>
<td>Cost (£110 pa) Time (100hrs pa DP)</td>
<td>3</td>
</tr>
<tr>
<td>1/2</td>
<td>Collaborate with other interested parties such as SIDS to promote an awareness of</td>
<td>Liaison with other groups, production of leaflet, mailing etc. (£500) plus</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>infant overheating among midwives and health visitors.</td>
<td>time (60 hrs DP/SA)</td>
<td></td>
</tr>
<tr>
<td>2/5</td>
<td>Support research financially by making grants.</td>
<td>Major financial input (surely we would need to consider grants of a minimum</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td></td>
<td>of £1000) but also time to develop administrative procedures, committee time</td>
<td></td>
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<td></td>
<td></td>
<td>to discuss applications (time needed initially upwards of 100 hrs DP/MAB/</td>
<td></td>
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<tr>
<td></td>
<td></td>
<td>Committee)</td>
<td></td>
</tr>
<tr>
<td>3/1</td>
<td>Diana Perry with the MAB to produce individual leaflets about the different ED</td>
<td>£100 and 50 hrs per leaflet (DP/MAB)</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>syndromes.</td>
<td></td>
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</tr>
<tr>
<td>4/3</td>
<td>Create a network of regional self-help groups (initial research &amp; contacts).</td>
<td>Time (75 hrs DP/SA)</td>
<td>4</td>
</tr>
<tr>
<td>4/4</td>
<td>Set up the database to facilitate the above.</td>
<td>Time (75 hrs SA)</td>
<td>4</td>
</tr>
<tr>
<td>4/5</td>
<td>Aim to devolve support by either appointing experts in particular fields such as</td>
<td>Time (100 hrs DP) for training</td>
<td>4</td>
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<tr>
<td></td>
<td>air conditioning or grant applications or by having regional co-ordinators who</td>
<td></td>
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<td></td>
<td>cover all aspects of support.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4/7</td>
<td>Diana &amp; Sue to go on tour setting up local support groups</td>
<td>Each meeting (total of 4) would involve on average one day and an overnight</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td></td>
<td>stay costing £150 and taking 20 hrs (Total: £600, 80 hrs DP/SA)</td>
<td></td>
</tr>
<tr>
<td>6/1</td>
<td>Give financial support to members in need for items such as air conditioning or</td>
<td>As 2/5 but individual contributions might include smaller amounts (£200-300)</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>cooling jackets.</td>
<td></td>
<td></td>
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<tr>
<td>6/2</td>
<td>Raise money specifically for a Support Fund for which we would invite applications.</td>
<td>See 2/5.</td>
<td>4</td>
</tr>
<tr>
<td>8/2</td>
<td>Increase the number of newsletters to 6 per year</td>
<td>Extra time and cost of two more editions: 60 hrs, £300 SA/DP</td>
<td>4</td>
</tr>
<tr>
<td>9/3 (b)</td>
<td>Improve content of ED website (cont): (d) more articles which include visual information; (e) more information on how ED affects individuals.</td>
<td>Time (d- variable; e- 50 hrs DP/DW)</td>
<td>4</td>
</tr>
</tbody>
</table>

CONCLUSION

At the Executive Committee Meeting on 8/5/04 it was decided to agree an action plan for the next twelve months. Progress in implementing this action plan would be reviewed at each Executive Committee Meeting with a thorough review being undertaken in May 2005 which would then lead to a new action plan for 2005-6.

The report is of course entitled “Looking Forward: The Next Three Years” and the Executive Committee felt that there was more than enough possible developments to keep us occupied for at least this period of time. It was felt best just to commit to both making a start and a process of constant review.

The Executive Committee also agreed to make the report and action plan available to the wider membership on request. They also hoped that the wider membership would comment on both the report and the initial action plan and in that way participate in the ongoing review process.

ACTION PLAN (2004-5)

The following was agreed:

- Implement all Category 1 Action Points (1/8, 1/9, 2/2, 2/4, 3/2, 4/1, 4/2, 4/6, 5/1, 8/1, 9/1, 9/3(a), 10.2, 10.3).
- Implement Category 2 Action Point 1/7.
- Ask MAB to consider implementing one of the following Category 3 Action Points: 1/3, 1/6, 2/1.
- Implement the linked Category 4 Action Points 6/1 and 6/2.