Final Report on the CAUSE Project
Funded by the European Commission.

Written by: Elizabeth Cook, Sense
Richard Hawkes, Sense International

June 2003 (updated December 2003)
1. Introduction

Deafblindness is a unique and isolating disability, which is more than a simple combination of visual and hearing impairments. Deafblind people face enormous challenges that are often exacerbated by a lack of awareness, among the public in general, of the cause and functional effects of their condition.

The European Union funded CAUSE project focused on two specific causes of deafblindness, Usher syndrome and CHARGE. The key aim of the project was to promote a wider awareness of these conditions through the exchange of information, experience and best practice between the CHARGE Network and the European Usher syndrome Network.

The CAUSE project ran from November 2001- April 2003 (Please refer to Appendix 1 “Revised Project Timetable”). The project was managed by the Voluntary Services Team, at Sense, in association with Sense International. This project was the first collaboration between the European Usher Syndrome Network and the CHARGE network. It was supported and monitored by seven European Project Partner organisations.

2. Summary of objectives and how they were met.

2.1. Organisation of a major joint conference.

The EUSN and CHARGE network held a joint conference in Hinckley, Leicestershire, UK from 27th – 30th March 2003. The conference was attended by 206 delegates; an additional 32 deafblind young people and their siblings took part in the Leisure club and the event was supported by 71 staff; general volunteers; communication support workers; Leisure club volunteers and entertainers.

The conference drew participants from 14 different countries (Appendix 2) and was officially opened by HRH Princess Anne, the Princess Royal.

The two networks met jointly at the conference to focus on two key themes “Adapting to change” and “Identity and being”. Keynote addresses were followed by panel presentations, in which people with Usher or CHARGE and family members were given an opportunity to
relate their unique experiences of living with these conditions. Speakers identified the resources that were important in enabling them to adapt to change and develop their identity.

Later in the programme (see Appendix 3) the individual networks met. The CHARGE network discussed recent developments in the field of medical research; explored some of the behavioural implications of CHARGE and linked this in with the initial findings of the collaborative study, supported by the project, into the behaviour of children with CHARGE. The Usher network invited keynote speakers from the field of genetic research. Later, Usher discussion groups developed the main themes of the conference, with reference to changes that current research may bring about. Research undertaken as part of the CAUSE project was presented within each network meeting.

2.2. Full meeting of the European Usher syndrome Network and the CHARGE Network.

Please refer to the above and to Appendix 4

Full meeting of the CHARGE Network.

See above and the report written by David Levey, Chair of the CHARGE Network.

2.3. Three project partner meetings.

These were attended by representative from the seven project partner organisations and held as follows:

1st December 2001  Sense
Finsbury Park, London
United Kingdom

18th/19th May 2002.  Ibis hotel
Poitiers, France
Key tasks undertaken at project partner meetings included:

- Drafting of the conference programme.
- Discussion on the fee structure for the conference and monitoring the practical aspects of the organisation, including communication support.
- Drafting of Usher and CHARGE fact sheets and bibliography.
- Agreeing an identity for the project, including a logo and project folder.
- Discussion on the format and method of dissemination of surveys undertaken by the project.

Please refer to the minutes of the meetings and Agenda / Information document for project partners.

2.5 Drafting and translation of information leaflets and information packs.

The project has produced the following information resources.

**CHARGE fact sheets**

- What is CHARGE?
- Living with CHARGE.
- Communication development in children with CHARGE.

These were drafted in English by the CHARGE sub-group of the project partners, reviewed by some CHARGE families in the UK and returned to the project partners for the final edit.

**Usher fact sheets**

- What is Usher syndrome?
- A history of Usher syndrome
- Living with Usher Type 1
- Living with Usher Type 2
- Living with Usher Type 3
Following a review of existing materials, the first two fact sheets were drafted by the project partners. The series of fact sheets “Living with Usher” are based on case studies and interviews with people with Usher, undertaken by individual project partners. These fact sheets include summarised guides to best practice and recommendations.

Bibliography.

The partners were asked to submit recommendations for the bibliography. The response was minimal, with the resultant document being largely based on resources recommended by the partner representative from Sense.

Video

The project produced a video from footage taken at the conference. This includes:

- An introduction to the project.
- Edited versions of the panel presentations by people with Usher and CHARGE and family members.
- A series of short interviews with people with Usher syndrome, based on the Usher Lifestyle Survey undertaken as part of the project. These interviews include individuals discussing the support and services that would be of benefit to them.
- Footage demonstrating the different forms of communication used by people with Usher and CHARGE, which may be used to illustrate references within the fact sheets produced by the Project.

Translation and dissemination of project resources.

The project folder includes a brief introduction to the CAUSE project in all the project partner languages, together with contact details for the partners.

Copies of the folder and headed paper were distributed to the project partners, who printed off translations of the fact sheets as required. Project partners have kept records of organisations and individuals to whom they sent print copies of the materials.
All fact sheets may be downloaded from the CAUSE pages on the Deafblind international Website:

www. Deafblindinternational.org/CAUSE/publications

The video is available in spoken English and British sign language. The budget for the project did not cover the provision of language subtitles or interpretation into other sign languages. The project partners have been offered the opportunity to fund this themselves.

2.6 Detailed survey - to cover existing early warning/ prevention systems and the nature and extent of services available in partner countries.

The project undertook the following surveys:

- A survey of existing support services for people with Usher and CHARGE living in the CAUSE project partner nations.

  This was conducted by email and is available in print and on the project Website.

- “Maintaining independence – A lifestyle survey of people with Usher Syndrome living in the CAUSE project partner nations”.

  The survey questionnaire was sent to a minimum of 12 individuals with Usher syndrome in each project partner country. Support in completing the questionnaires was provided by project partners. Results were collated and the survey report prepared by Liz Cook and Marylin Kilsby at Sense. The survey focused on existing provision, relationships and identity, and the challenges that people with Usher face.

  The survey results were presented during the EUSN meeting at the CAUSE conference and again at the Deafblind International World Conference held in Toronto, Canada in August 2003.

- Behavioural study of children with CHARGE.

  The CAUSE project partners agreed that the project should promote the wider dissemination of two existing surveys into the behaviour of children with CHARGE:
Questionnaire for families of children with CHARGE syndrome.
Dr. Jacques Souriau, Director, CRESAM
This was translated and disseminated in print form through the project partners.

Challenging behaviours in CHARGE syndrome.
Professor Timothy Hartshorne.
Professor of Psychology, Central Michigan University, United States of America.
This was made available through Professor Hartshorne’s website: www.chsbs.cmich.ed/timothy_hartshorne/

Results were presented by Dr Souriau and Professor Hartshorne at the CAUSE conference. If we are able to secure further funding it may be possible to review these surveys in more detail. This would be undertaken by Dr Peter Hindley, Cornerhouse Deaf Child and Family Service, National Deaf Services, United Kingdom. Dr Hindley has worked in collaboration with Dr Souriau and Professor Hartshorne.

2.7. Ongoing data collection and research; dissemination to partners and wider general and medical communities.

Data and information have been collected and disseminated through the three CAUSE surveys and through the published proceedings of the CAUSE conference.

2.8. Formulations of recommendations and guides to best practice.

Recommendations and summarised guides to best practice form an integral part of the resources produced by the CAUSE project; appearing in the fact sheets, conclusion to the Usher Lifestyle survey and anecdotally within CAUSE project video.

3. Expected results of the project.
The activities of the project broadly relate to the expected results as set out in section 7 of the project funding application. Please note comments relating to the following points:

3.1 Presentation of networks and dissemination of current research at the DbI World Conference, Toronto, Canada, August 2003.

The following papers were presented at the network day at the DbI conference.

“Maintaining and expanding an Usher network across Europe and beyond”  
A paper on the development of the EUSN.

“Maintaining Independence: a report on the Usher lifestyle survey undertaken as part of the EU CAUSE project”

Additionally, the conference was used as an opportunity to disseminate research findings and share resources produced by the project, with a wider audience.

3.2. Two general information leaflets and two detailed information packs (one for each syndrome).

The project produced five leaflets on Usher syndrome, including leaflets specific to Usher type I, II, and III.
Additionally three leaflets on CHARGE have been produced.
The project folder allows for individual packs to be created according to specific requirements.

3.3. Two surveys: one on existing early warning/prevention systems and one on the nature and extent of services available in partner countries.

No prevention systems currently exist for Usher or CHARGE (the cause of CHARGE continues to be researched).
Early in the project, the project management team at Sense recognised that, in the case of both Usher and CHARGE, project resources would be most effectively invested in promoting awareness of the diagnostic criteria of CHARGE and of the early indicators of Usher. By agreement with the partners this has been done through the information fact sheets produced by the project and the Conference proceedings. By agreement with the project partners, the CAUSE project undertook a
lifestyle survey of people with Usher syndrome and promoted the wider dissemination of two behavioural surveys of children with CHARGE.


Recommendations and summarised guides to best practice form an integral part of the resources produced by the CAUSE project. Eight fact sheets were produced as part of this project, as well as the Usher Lifestyle survey and the CAUSE project video. The fact sheets on the different types of Usher identify communication, mobility and future needs that it would be best practice for services to meet. The Usher Lifestyle survey, clearly identifies the voice of people with Usher, the lifestyles they want to lead and the support they need to enable them to do so. Responding to this agenda, laid down by people with Usher, would be good practice for any agency providing support.

The presentations on CHARGE, by David Brown and others, represent the latest thinking on issues facing individuals with CHARGE and offer clear ideas on the best way to address these issues. For example Jacques Souriau identified how families and professionals can be good partners for people with CHARGE. A quote from the UK CHARGE Family Support Group illustrates how participants drew out ideas of good practice from the presentations.

"From these he tried to draw conclusions relating to teamwork, priorities, one thing at a time and behaviour. For me David’s illustration of asking the various people in an assessment (professionals, parents) what a child is doing stood out where each person saw only what they wanted. I believe this related to ‘one thing at a time’ where he said ‘only the clearest view and the strongest empathy will help people to gain any insight of what an activity really means for the child’. Basically we need to try to understand what the child’s perception of what you are trying to do and where his/her attention is most likely to be focussed."

3.5 Website

CAUSE pages have been posted on the Deafblind International website www.deafblindinternational.org. The content of the website has included background to the project information about the EUSN and the CHARGE network and information about the conference. The proceedings of the conference, the fact sheets and the survey reports are all on the website.
4. **Evaluation and consultation.**

The following methods of consultation were used in order to evaluate the project.

- **Project partner meetings**
  Partners were directly consulted about all aspects of the management of the project at partner meetings.

- **Email contact with project partners.**

- **Email contact with non-partner members of the CHARGE and Usher sub-groups.** Additional members were recruited to these sub-groups by the project partners. This additional membership included people directly affected by the condition and professionals from non-partner organisations. Consultation took place on the conference and on the development of the surveys and information packs.

- **Evaluation of information resources by people with CHARGE and Usher and their families.**
  A wider group of people with CHARGE and Usher and their families were involved in the final editing of the fact sheets.

- **Feedback from the conference**
  All participants at the conference were invited to complete a feedback form, relating to the conference programme and practical arrangements. Feedback from conference delegates, speakers and facilitators and communication support workers will greatly assist with the planning of future events of this nature.
5. **Summary and conclusion**

The success of the CAUSE project may be gauged against the following key indicators:

- The project has facilitated the development of the CHARGE and Usher Networks and in the process has stimulated discussions on areas of commonality and created a model for possible future joint initiatives.

- The membership of the EUSN has to date increased by 120% (the increase in membership of the CHARGE Network has yet to be quantified).

- Links have been created not only between families and professionals at a national and European level, but also with professionals and other networks in North America.

- The project has stimulated joint working specifically in the field of CHARGE Behavioural research.

- An accessible range of up to date information resources has been made available to partner countries, where previously none existed e.g. Ireland now has its own information resource on CHARGE.

- The project has supported people with Usher and CHARGE to advocate their own needs and to celebrate their achievements and their identity. It has used case studies to generate awareness of the day-to-day challenges of living with Usher syndrome or CHARGE.
Appendix 1

**CAUSE project**

**Revised Timetable**

<table>
<thead>
<tr>
<th>Date</th>
<th>Location</th>
<th>Activity</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nov 1st 2001</td>
<td>UK</td>
<td>Appointment of project co-ordinator.</td>
</tr>
<tr>
<td>Dec 1st 2001</td>
<td>UK</td>
<td>First project partner meeting.</td>
</tr>
<tr>
<td>Dec – May 2002</td>
<td>Project partner nations.</td>
<td>Ongoing data collection</td>
</tr>
<tr>
<td>May 18th/19th</td>
<td>France</td>
<td>Second project partner meeting.</td>
</tr>
<tr>
<td>May – Oct 2002</td>
<td>Project partner Nations.</td>
<td>Planning of conference Drafting of surveys</td>
</tr>
<tr>
<td>Oct 17th-20th 2002</td>
<td>Italy</td>
<td>Third project partner meeting. Drafting of fact sheets. Conference planning</td>
</tr>
<tr>
<td>March 27-30th 2003.</td>
<td>UK</td>
<td>CAUSE conference, Full meeting of the CHARGE Network and the EUSN.</td>
</tr>
<tr>
<td>April 30th 2003.</td>
<td></td>
<td>Completion of project</td>
</tr>
</tbody>
</table>
Appendix 2

Nations represented at the CAUSE conference.

Canada
Denmark
France
Germany
Hungary
Ireland
Israel
Italy
Norway
Spain
Sweden
Switzerland
The Netherlands
United Kingdom
United States of America
# Appendix 3

## CAUSE Conference Programme

<table>
<thead>
<tr>
<th>Date /Time</th>
<th>Date and Time</th>
</tr>
</thead>
</table>
| Thursday 27\textsuperscript{th} March 2003. | Arrival  
Welcome receptions  
Dinner |
| Afternoon | |
| Friday 28\textsuperscript{th} March 2003. | Communications Check. |
| 9.45am |  |
| 10.00am | Introduction to the CAUSE project.  
Official opening of the CAUSE conference by HRH the Princess Royal. |
<p>| 11.00am | Coffee |</p>
<table>
<thead>
<tr>
<th>Time</th>
<th>Event</th>
</tr>
</thead>
</table>
| 11.30am | Plenary presentation "Adapting to Change"  
Dr Margaret du Feu. |
<p>| 12.15pm | Panel presentation.                                                   |
| 1 - 2pm  | Lunch                                                                 |
| 2 - 5pm  | CHARGE and Usher Network meeting.                                     |
|         | Usher                                                                 |
|         | Presentation on research into Usher.                                  |
|         | Dr. Bill Kimberling                                                  |
|         | Professor Claes Moller                                               |
|         | Followed by workshops                                                |
|         | CHARGE Network                                                       |
|         | Presentation on &quot;Sensory Behaviour&quot;                                  |
|         | David Brown.                                                         |
|         | Presentation on the CHARGE Behavioural survey.                       |
|         | Dr. Timothy Hartshorne                                               |</p>
<table>
<thead>
<tr>
<th>Time</th>
<th>Event</th>
</tr>
</thead>
<tbody>
<tr>
<td>7pm</td>
<td>Usher Forum Theatre Presentation.</td>
</tr>
<tr>
<td>8pm</td>
<td>Dinner</td>
</tr>
<tr>
<td></td>
<td><strong>Saturday 29(^{th}) March 2003.</strong></td>
</tr>
<tr>
<td>9.45am</td>
<td>Communication check</td>
</tr>
<tr>
<td>10.00am</td>
<td>Plenary presentation</td>
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<tr>
<td></td>
<td>&quot;Identity and Being&quot;</td>
</tr>
<tr>
<td></td>
<td>Carol Brill-Doran</td>
</tr>
<tr>
<td></td>
<td>Member of the EUSN from Ireland.</td>
</tr>
<tr>
<td></td>
<td>Followed by panel presentation.</td>
</tr>
<tr>
<td>11.30am</td>
<td>Coffee</td>
</tr>
<tr>
<td></td>
<td>Usher workshops on</td>
</tr>
<tr>
<td></td>
<td>&quot;Identity and Being&quot;</td>
</tr>
<tr>
<td></td>
<td><strong>CHARGE</strong></td>
</tr>
<tr>
<td></td>
<td>&quot;Sensory Integration: a special challenge for CHARGE&quot;</td>
</tr>
<tr>
<td></td>
<td>David Brown</td>
</tr>
<tr>
<td>1-2pm</td>
<td>Lunch</td>
</tr>
</tbody>
</table>
2.30pm - 5.30pm

Network meetings
(Tea at 4pm)

Usher Network

Presentation on the Usher Lifestyle survey.
Marylin Kilsby.

Where does the EUSN go from here?
A discussion on the future of the EUSN.
Chaired by Peter Palmer.

Followed by workshops on the following themes:
* Peer mentoring.
* Technology
* Support groups

CHARGE
Presentations on
The Sense of vestibular balance in CHARGE. Vincent Couloigner.
Olfaction deficiency: a major criteria of CHARGE. Veronique Abadie.
"Communication in CHARGE"
Jacques Souriau
Each followed by discussion.
<table>
<thead>
<tr>
<th>Time</th>
<th>Event</th>
</tr>
</thead>
<tbody>
<tr>
<td>8pm</td>
<td>Dinner</td>
</tr>
<tr>
<td></td>
<td>The English Pocket Opera Company.</td>
</tr>
<tr>
<td></td>
<td>Followed by disco</td>
</tr>
<tr>
<td>Sunday 30\textsuperscript{th} March 2003.</td>
<td></td>
</tr>
<tr>
<td>10am</td>
<td>Review of the conference</td>
</tr>
<tr>
<td></td>
<td>Malcolm Matthews</td>
</tr>
<tr>
<td></td>
<td>Close of the CAUSE conference</td>
</tr>
<tr>
<td>10.45am</td>
<td>Coffee</td>
</tr>
<tr>
<td></td>
<td>EUSN committee meeting</td>
</tr>
<tr>
<td></td>
<td>CHARGE committee meeting</td>
</tr>
<tr>
<td></td>
<td>CAUSE editorial meeting</td>
</tr>
<tr>
<td>1pm</td>
<td>Lunch and depart</td>
</tr>
</tbody>
</table>
Appendix 4

CAUSE Project – Involvement of the European Usher Syndrome Network (EUSN)

Level of Involvement of the EUSN

The EUSN was one of the two Networks for which the CAUSE Project was set up. Marylin Kilsby was the EUSN representative on the CAUSE Project. She has taken part in the Project from the start and has been responsible both for the Usher programme for the conference and for liaising with the EUSN in general.

The EUSN members have been involved throughout the project, from the initial consultation meeting in November 2001, right through and beyond the conference in March 2003. Some EUSN members also took part in the Usher Lifestyle Survey, which was distributed to the partner nations via their CAUSE representatives.

Benefits of the EUSN Involvement

- An increase in membership. Following the conference, the number of members has increased from 18 to 41 and new applications are still coming in. Most of the new members have Usher Types 1 or 2 or are deaf.

- Provision of clear but simple fact sheets on the three types of Usher, the history of Usher development, the genetics of Usher and a bibliography will be circulated to all members.

- The increase in membership and the publicity of the EUSN throughout the CAUSE project is likely to expand the potential of the EUSN, including enabling the group to be able to nominate a representative on Dbl.

Developing the EUSN in the future

The benefits outlined above will continue after the life of the CAUSE Project. The fact sheets and the Usher lifestyle survey will be available in a variety of formats, including on the CAUSE Website. The EUSN will
be able to make use of these materials both as resources and as publicity for the EUSN.

A major result of the CAUSE project is the production of two videos. The main CAUSE video which will include all the panel presentations, all of which feature at least one Usher person and / or a parent of an Usher person. The video will also include excerpts from filmed interviews linked with the Usher Lifestyle Survey.

In addition to the main CAUSE video, a special video of the Genetics of Usher presentations by Professor Bill Kimberling and Professor Claes Möller has been made. This video is available with or without British Sign Language interpretation and also in transcript form. Carol Brill Doran, Secretary of the EUSN, is the Chair of this session. We plan to use this video in many training situations both within Sense and with staff in various agencies, including social work / welfare departments, schools and audiology / retinal clinics. The video will be made available to the Project partners.

Conclusion

The CAUSE project has revitalised the EUSN and increased its membership to date by 120%. This growth should continue and, we trust, lead to an organisation that will be not only a much needed Network but also an information provider and a real voice on DbI. This will enable the EUSN to influence the lifestyles of Usher people throughout Europe and beyond.

Marylin Kilsby
National Usher Co-ordinator
17.06.03
## APPENDIX 5

### List of CAUSE Conference Participants

<table>
<thead>
<tr>
<th>Name</th>
<th>Position</th>
<th>Country</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mrs V Abadie</td>
<td>Speaker</td>
<td>France</td>
</tr>
<tr>
<td>Ms J Ackerman</td>
<td>Delegate</td>
<td>UK</td>
</tr>
<tr>
<td>Mr B Aguirre</td>
<td>Delegate</td>
<td>France</td>
</tr>
<tr>
<td>Ms R Alley</td>
<td>Delegate</td>
<td>UK</td>
</tr>
<tr>
<td>Mr N Alvi</td>
<td>Delegate</td>
<td>UK</td>
</tr>
<tr>
<td>Mr O Andersen</td>
<td>Delegate</td>
<td>Denmark</td>
</tr>
<tr>
<td>Rhian Angharad</td>
<td>Sense Cymru</td>
<td>UK</td>
</tr>
<tr>
<td>Abigail Apps</td>
<td>Leisure Club Volunteer</td>
<td>UK</td>
</tr>
<tr>
<td>Mrs R Arcones</td>
<td>ONCE</td>
<td>Spain</td>
</tr>
<tr>
<td>Mr F Ardizzino</td>
<td>Lega del Filo d'Oro</td>
<td>Italy</td>
</tr>
<tr>
<td>Mrs D Arnaud</td>
<td>Usher Theatre Group</td>
<td>UK</td>
</tr>
<tr>
<td>Ian Arnold</td>
<td>Delegate</td>
<td>UK</td>
</tr>
<tr>
<td>Ross Arnold</td>
<td>Leisure Club User</td>
<td>UK</td>
</tr>
<tr>
<td>Yvonne Arnold</td>
<td>Delegate</td>
<td>UK</td>
</tr>
<tr>
<td>Zara-Jayne Arnold</td>
<td>Leisure Club User</td>
<td>UK</td>
</tr>
<tr>
<td>Ms B Arregui Noguer</td>
<td>ONCE</td>
<td>Spain</td>
</tr>
<tr>
<td>Hetty Bailey</td>
<td>Interpreter Co-ordinator</td>
<td>UK</td>
</tr>
<tr>
<td>Mrs B Baker</td>
<td>Delegate</td>
<td>UK</td>
</tr>
<tr>
<td>Master E Bargeman</td>
<td>Leisure Club User</td>
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<td>Delegate</td>
<td>UK</td>
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<tr>
<td>Master L Bargeman</td>
<td>Leisure Club User</td>
<td>UK</td>
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<tr>
<td>Mr S Bargeman</td>
<td>Delegate</td>
<td>UK</td>
</tr>
<tr>
<td>Mrs S Barker</td>
<td>Delegate</td>
<td>UK</td>
</tr>
<tr>
<td>Colin Bennett</td>
<td>Delegate</td>
<td>UK</td>
</tr>
<tr>
<td>Simon Bennett</td>
<td>Delegate</td>
<td>UK</td>
</tr>
<tr>
<td>Tony Best</td>
<td>Chief Executive Sense</td>
<td>UK</td>
</tr>
<tr>
<td>Samantha Bissett</td>
<td>Sense staff</td>
<td>UK</td>
</tr>
<tr>
<td>Corinne Blouin</td>
<td>Delegate</td>
<td>France</td>
</tr>
<tr>
<td>Eileen Boothroyd</td>
<td>Sense Staff</td>
<td>UK</td>
</tr>
<tr>
<td>Mylene Bovis</td>
<td>CRESAM</td>
<td>France</td>
</tr>
<tr>
<td>Paula Bowers</td>
<td>Delegate</td>
<td>UK</td>
</tr>
<tr>
<td>Mrs A Brill</td>
<td>Communicator Guide</td>
<td>UK</td>
</tr>
<tr>
<td>Carol Brill-Doran</td>
<td>Speaker</td>
<td>Ireland</td>
</tr>
<tr>
<td>Marisol Briosol Montaner</td>
<td>Delegate</td>
<td>Spain</td>
</tr>
<tr>
<td>Elizabeth Brodie</td>
<td>Delegate</td>
<td>UK</td>
</tr>
<tr>
<td>Jennifer Brodie</td>
<td>Delegate</td>
<td>UK</td>
</tr>
<tr>
<td>Master R Brodie</td>
<td>Leisure Club User</td>
<td>UK</td>
</tr>
</tbody>
</table>
Andrew Broughton  Delegate     UK
David Brown   Speaker      USA
Katherine Brown  Leisure Club Volunteer  UK
Norman Brown  Delegate     UK
Sue Brown   Sense Staff    UK
Helen Butler   Delegate     UK
Keith Butler   Delegate     UK
Angela Carruthers   Delegate     UK
Miss R Carruthers  Leisure Club User    UK
Patrizia Ceccarani  Lega del Filo d'Oro   Italy
Magda Ceeberg   Delegate     Norway
Christel Chalouhi   Delegate     France
Richard Chattell   Sense East     UK
Sarah Chippindale  Leisure Club Volunteer  UK
Arlette Churakowskyi  Delegate     France
Bruno Churakowskyi  Delegate     France
Miss G Churakowskyi  Leisure Club User    France
Miss L Churakowskyi  Leisure Club User    France
Mr Y Churakowskyi  Leisure Club User    France
Monica Clarke   Leisure Club Volunteer  UK
Mr J Cleverton   Guest     UK
Eileen Clifford   Sense      UK
Kevin Clough   Sense       UK
Anne Constantin   Delegate     Switzerland
Liz Cook   Sense Organiser   UK
Michael Corney   Delegate     UK
Silvia Corridori  Delegate     UK
Vincent Couloigner  Delegate     UK
Angela Cowie   Delegate     UK
Master C Cowie  Leisure Club User    UK
Raymond Cowie  Delegate     UK
Sally Damslora  Delegate     Norway
Sandrine Dangleterre   CRESAM     France
Sue Davies  Sense Staff    UK
Peter Deckett  Leisure Club Volunteer  UK
Margaret de Feu   Speaker      UK
Gail Deuce  Sense Staff    UK
Gregory Draper  Leisure Club User    UK
Nicholas Draper   Delegate     UK
Sheila Draper      Delegate     UK
Ilan Dwek         Interpreter     UK
Wendy Ebsworth MBE Interpreter Co-ordinator  UK
Christine Engelbach Delegate     France
Nicky Ereaut      Delegate     UK
Esther Escobar    Delegate     Spain
Sally Ferguson    Delegate     UK
Lester Ferguson   Delegate     UK
Ma Angeles Fernandez ONCE     Spain
Ms M Fielder     Interpreter     UK
Ben Fletcher      Delegate     UK
Jenny Fletcher    Sense Staff     UK
Daniel Fleuty    Delegate     UK
Master D Fleuty   Leisure Club User     UK
Gemma Fleuty     Delegate     UK
Master H Fleuty   Leisure Club User     UK
Jannice Floyd    Sense Staff     UK
Darren Forster   Leisure Club Volunteer     UK
Mary Foster       Sense Staff     UK
Mr D Fox         Guest     UK
Mariano Franco Rolo ONCE     Spain
Jo Franklin       Delegate     UK
Christopher Fuggle Sense Staff     UK
Live Fuglesang  Delegate     Norway
Marcia Gaynor    Leisure Club Volunteer     UK
Mary Ghatineh    Delegate     UK
Lisa Gibbs       Leisure Club Volunteer     UK
Crystal Gibson   Leisure Club Volunteer     UK
Alisa Gillett    Delegate     UK
Thelma Goddard   Leisure Club Volunteer     UK
Daniel Goldberg  Delegate     UK
Gwynne Goldberg Meijer Delegate     UK
Miss J Goldberg  Leisure Club User     UK
Pilar Gomez-Vinas ONCE     Spain
Isabel M Gracia" ONCE     Spain
Lina Graham"     Delegate     UK
William Green    CAUSE Conference Chair,
                 Lega del Filo d'Oro     Italy
                 Speaker
Ann Grummitt   Interpreter     UK
Tony Grummitt   Volunteer     UK
Mary Guest   Sense Staff     UK
Eran Gur   Delegate     Israel
Genet Habtemariem   Lega del Filo d'Oro     Italy
Frances Hampton   Sense Staff     UK
Niel Hanshaw   Leisure Club Leader
Mr T Hartshorne   Speaker     USA
Richard Hawkes   Director Sense International     UK
Libby Hawkins   Organiser Sense     UK
Fred Hayles   Delegate     UK
Julie Hazelhurst   Delegate     UK
Zane Hema   Interpreter     UK
MissH Henderson   Leisure Club User     UK
Rob Henderson   Delegate     UK
Trina Henderson   Delegate     UK
Anja Hess   Leisure Club Volunteer     UK
Yvonne Higgins   Delegate     UK
Jessica Hills MBE   Delegate     UK
Peter Hines-Tabner   Leisure Club Volunteer     UK
Alan Hornblow   Guest     UK
Miss E Howard   Leisure Club User     UK
Miss J Howard   Leisure Club User     UK
Simon Howard   Delegate     UK
Lisza Hoyer   Delegate     UK
Liz Hughes   Delegate     UK
Catherine Hutter   Delegate     Switzerland
Nuria Ibanez   ONCE     Spain
Vessela Ivanova   Interpreter     Spain
Linda Jardine   Delegate     UK
Hanneke Kapteyns   Delegate     Holland
Marylin Kilsby   Organiser
                      National Usher Co-ordinator     Sense     UK
Dr Bill Kimberling   Speaker     USA
Rick King   Interpreter     UK
Julia Knights   Guide Communicator
Anny Koppen   Delegate     Denmark
Gudrun Lemke-Werner  Delegate  Germany
David Levey  Organiser  
Hanna Levey  Delegate  UK
Joshua Levey  Leisure Club User  UK
Rebecca Levey  Leisure Club User  UK
Yoachim Levey  Leisure Club User  UK
Linda Linnett  Interpreter  UK
Susy Lithman-Romeo  Speech to Text Interpreter  UK
Aleka Loizou  Delegate  UK
Valter Longoni  Lega del Filo d'Oro  Italy
Alison Lovett  Interpreter  UK
Soledad Lopez  Delegate  Spain
Mr L Buzzoni  Lega del Filo d'Oro  Italy
Richard Lucas  RNIB  UK
Claire Lyon  Leisure Club Leader  UK
Eric Magna  Delegate  France
Fabien Magna  Delegate  France
R Mahmood  Leisure Club User  UK
Tazeem Mahmood  Delegate  UK
Tariq Mahmood  Delegate  UK
Ashak Manji  Delegate  UK
F Manji  Leisure Club User  UK
I Manji  Leisure Club User  UK
Shelina Manji  Delegate  UK
Julia Marshall  Leisure Club Volunteer  UK
Katja Martin  Leisure Club Volunteer  UK
Desmond Masterson  Delegate  UK
Malcolm Matthews  Director CSI, Sense  UK
Joff McGill  Organiser Sense  UK
Kristian Merser  Delegate  Denmark
Connie Miles  Delegate  USA
Anne Millar  Delegate  UK
Simon Minter  Delegate  UK
Claes Moller  Speaker  Sweden
Marie Molnar  Delegate  Sweden
Barbara Moore  Sense Staff  UK
John Morgan  Interpreter  UK
Pamela Morgan  Interpreter  UK
Nermin Moustafa Delegate UK
Yvonne Mqadi Delegate UK
Elaine Murray-Bell Delegate UK
Miss E Murray-Bell Leisure Club User UK
MasterJ Murray-Bell Leisure Club User UK
Wahida Nagi Delegate UK
Marco Nardi Interpreter UK
Florence Njeru Delegate UK
Graham Nolan Sense Staff UK
Jonathan Norris Leisure Club Volunteer UK
Jytte Olsen NUD Denmark
Hannah Ormsby Leisure Club Volunteer UK
Ivan Osborne Interpreter UK
Peter Palmer European Usher
Mark Pampel Delegate UK
Jeannette P Patching HSI UK Chair UK
Miss A Payne Leisure Club User UK
Barbara Payne Delegate UK
Mr C Payne Leisure Club User UK
John Payne Delegate UK
Albert Pearce Delegate UK
Fiona Pearl Delegate UK
Jordan Peckett Leisure Club User UK
Tricfia Pereira Delegate UK
Iolo Rhys Leisure Club Leader UK
Margaret Pickess HSI UK UK
Stefania Pigliapoco Lega del Filo d'Oro Italy
Hanne Pittroff Delegate Germany
Carol Pollington Sense North UK
Clive Pollington Delegate UK
Sarah Reed Sense Staff UK
Iolo Rhys Leisure Club Leader UK
Christine Richards Delegate UK
Ms F Ridgewell Delegate UK
Liz Rieley Leisure Club Volunteer UK
Dawn Rimmer Leisure Club Volunteer UK
Mrs C Rivalin Delegate France
Mr D Robertson Guest UK
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<tr>
<th>Name</th>
<th>Role</th>
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<tr>
<td>Miss J Roberts</td>
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<tr>
<td>Carol Thomas</td>
<td>CHARGE Family Support Group Chair</td>
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<tr>
<td>James Thomas</td>
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Claudia Thon  Delegate     UK
Mr M Tinkler   Guest     UK
Bruno Tiranti  Delegate     UK
Hannah Tompkins Leisure Club Volunteer  UK
Jenny Towland  Interpreter     UK
Lindsey Truss  Delegate     UK
Jackie Turner  Delegate     UK
Mark Turner    Volunteer     UK
Charlie A Turrell Delegate     UK
Melanie Ulyatt  Delegate     UK
Linda Upson    Delegate     UK
Claudio Valdes  Delegate     Spain
Mr D Valentine Interpreter     UK
Charlotte van de Molengraft Delegate     The Netherlands
Sonja van de Molengraft Delegate     The Netherlands
Marella van den Boom Delegate     The Netherlands
Mieke van Kollenburg Delegate     The Netherlands
Gloria Ward     Sense Staff    UK
Claire Waterman Sense Staff    UK
Sheila Whibley Leisure Club Leader  UK
Anita Whitehouse Communicator Guide     UK
Ms H Williams   Guest     UK
Rachel Williams Interpreter     UK
Pam Winters    Communicator Guide     UK
Paul Woodham   Leisure Club Volunteer  UK
Andrea Woodrow-Bennett Delegate     UK
Mr A Woodrow-Bennett Leisure Club User   UK
Mr L Woodrow - Bennett Leisure Club User   UK
Claire Wrather  Delegate     UK
Miss M Wrather  Leisure Club User   UK
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