



# **Usher Syndrome Project**

## **Evaluation Report**

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# 1 Introduction

Deafblind UK is committed to supporting people with Usher Syndrome <sup>1</sup>, as part of our work in the deafblind <sup>2</sup> community. Since its inception in 1989, Deafblind UK's Scottish office had been concerned that people with Usher Syndrome, particularly in Scotland, were often unidentified and isolated without access to organisations that might offer information, advice and support.

In April 1997 Deafblind UK's Scottish office was delighted to receive funding from the National Lottery Charities Board Scotland to support an important 3 year Usher Syndrome Project in Scotland. The Usher Syndrome Project was established in June 1997 and Stephen Joyce, who has Usher Syndrome, was appointed as the Co-ordinator.

## 2 Usher Syndrome

Usher Syndrome (Usher) is a genetic disorder that results in a hearing loss from birth combined with a progressive loss of vision due to Retinitis Pigmentosa. See Appendix one for further information.

## 3 Communication

People who have Usher Syndrome use a wide range of communication methods including British Sign Language, Speech, Hearing, Lip-reading, Deafblind Manual, Hands-on signing, Block Alphabet or a combination of several of these.

## 4 Estimated Numbers

Whilst there is no definitive incidence figure for Usher Syndrome several sources provide estimated incidence figures.

The Social Service Inspectorate "Signpost" Report of 1989 <sup>3</sup> gives the incidence of deafblindness as 2:10,000. The Department of Health Guidelines "Think Dual Sensory" (1995) <sup>4</sup> estimates that a figure of 4:10,000 is more realistic.

It is estimated that there may be as many as 337 as yet unidentified people with Usher Syndrome in Scotland.

Appendix two gives expected numbers of deafblind people for each Scottish local authority, based on this figure <sup>5</sup>. The figures give the expected number of people who may have Usher Syndrome. Current analysis of membership in Scotland shows that approximately 1 in 5 deafblind people may have Usher Syndrome.

## 5 Project Aims:

1. To raise awareness of Usher Syndrome.
2. To identify people with Usher in the deaf community, blind community and in the general population.
3. To provide information and on-going support to people with Usher and their families.
4. To increase public awareness of the daily problems caused by having Usher.
5. To train volunteers who have Usher to undertake this work in their own community.

## 6 Achievements



## **7 Difficulties encountered**

A wide range of communication skills is required to work with people who have Usher Syndrome. This inevitably causes problems in staff recruitment particularly interpreter support.

Usher Syndrome is a very low incidence disability. Most professional people have never encountered Usher Syndrome and are therefore reluctant to spend time learning about it.

The diagnosis of Usher Syndrome is for many people a shattering blow from which recovery is slow and painful. Deafblind UK is aware of more than 20 people who have Usher Syndrome and that information is shared only with close family. This makes identification of people with Usher Syndrome extremely difficult, especially in the deaf community.

Public awareness of Usher Syndrome is slowly increasing but again most people have never met anyone with Usher Syndrome and are unaware of the implications.

The recruitment and training of volunteers who have Usher Syndrome proved difficult as most had little confidence. However there is now a small core group of volunteers.

## **8 Evaluation Questionnaire**

### **8.1 Purpose**

In the final year of the Usher Syndrome Project a questionnaire was distributed to collect evidence regarding achievement of the project.

### **8.2 Methodology**

Depending on the communication method preferred, evidence was gathered using:

- A written questionnaire also in Large Print (see Appendices 3 and 4)
- Face to face interviews
- Telephone interviews

### 8.3 The response

- 1535 questionnaires were distributed during the third quarter of 1999. By the end of November, 515 replies had been received, a response rate of 34%.

Response by groupings

<b>Group</b>	<b>Sent out</b>	<b>Replied</b>	<b>Replies as a %</b>
Usher People	32	22	69
Deaf Organisations	21	14	67
Social Workers (HI or VI)	86	46	53
Audiologists	49	26	53
Ophthalmologists	75	38	51
Blind Organisations	49	23	47
ENT Specialists	60	23	38
GP's	861	279	32
Deafblind Organisations	11	3	27
Usher Roadshow attendees	136	35	26
Deaf Club	25	5	20
Education (HI or VI)	130	1	1
<b>Total</b>	<b>1535</b>	<b>515</b>	<b>34</b>

#### Question 1

Before receiving this questionnaire, did you know about Usher Syndrome?

<b>Yes</b>	<b>260</b>	<b>52%</b>
<b>No</b>	<b>239</b>	<b>48%</b>

#### Question 1a

If YES, from where did you find out about Usher Syndrome?

<b>DBUK/Usher Project</b>	<b>56</b>	<b>20%</b>
<b>Roadshows</b>	<b>28</b>	<b>10%</b>
<b>Publicity Material</b>	<b>57</b>	<b>20%</b>
<b>Other</b>	<b>145</b>	<b>51%</b>

#### Question 2

Do you have ready access to information about Usher Syndrome?

<b>Yes</b>	<b>188</b>	<b>39%</b>
<b>No</b>	<b>296</b>	<b>61%</b>

#### Question 2a

If YES, in which format is it available in?

<b>Normal Print</b>	<b>163</b>	<b>70%</b>
<b>Large Print</b>	<b>28</b>	<b>12%</b>
<b>Moon</b>	<b>1</b>	<b>0%</b>
<b>Braille</b>	<b>5</b>	<b>2%</b>
<b>BSL Video</b>	<b>10</b>	<b>4%</b>
<b>Audio Tape</b>	<b>6</b>	<b>3%</b>
<b>Other</b>	<b>20</b>	<b>9%</b>

Question 2b

If NO, where would you try to find information on Usher Syndrome?

<b>Deafblind UK</b>	<b>162</b>	<b>28%</b>
<b>Sense</b>	<b>49</b>	<b>8%</b>
<b>Health Centre</b>	<b>18</b>	<b>3%</b>
<b>Blind Club/Society</b>	<b>40</b>	<b>7%</b>
<b>Deaf Club/Society</b>	<b>35</b>	<b>6%</b>
<b>Social Work</b>	<b>36</b>	<b>6%</b>
<b>ENT Department</b>	<b>58</b>	<b>10%</b>
<b>Eye Department</b>	<b>55</b>	<b>9%</b>
<b>Audiologist</b>	<b>25</b>	<b>4%</b>
<b>Other</b>	<b>108</b>	<b>18%</b>

Question 3

Do you know anyone who may have undiagnosed Usher Syndrome?

<b>None</b>	<b>222</b>	<b>84%</b>
<b>1</b>	<b>6</b>	<b>2%</b>
<b>2-5</b>	<b>17</b>	<b>6%</b>
<b>6-10</b>	<b>5</b>	<b>2%</b>
<b>Don't Know</b>	<b>15</b>	<b>6%</b>

#### Question 4

What would help you at the time of Usher Syndrome diagnosis?

<b>Easy access to info</b>	<b>277</b>	<b>31%</b>
<b>Comm. Support</b>	<b>92</b>	<b>10%</b>
<b>Contact with Usher Org</b>	<b>183</b>	<b>21%</b>
<b>Appropriate Support</b>	<b>109</b>	<b>12%</b>
<b>Leaflets</b>	<b>225</b>	<b>25%</b>
<b>Other</b>	<b>8</b>	<b>1%</b>

#### Question 5

What have been the benefits to you, if any, from Deafblind UK's Usher Syndrome Project?

<b>Easily Avail. Information</b>	<b>94</b>	<b>23%</b>
<b>Training</b>	<b>26</b>	<b>6%</b>
<b>Awareness</b>	<b>140</b>	<b>35%</b>
<b>Advice/support</b>	<b>31</b>	<b>8%</b>
<b>None</b>	<b>108</b>	<b>27%</b>
<b>Other</b>	<b>5</b>	<b>1%</b>

#### Question 6

Do you think you have enough information on all aspects of Usher Syndrome?

<b>Yes</b>	<b>139</b>	<b>34%</b>
<b>No</b>	<b>268</b>	<b>66%</b>

#### Question 6a

Would you like information? Please tick as many as needed:

<b>Helpful org</b>	<b>192</b>	<b>28%</b>
<b>Usher Project/DBUK</b>	<b>147</b>	<b>22%</b>
<b>Training opportunities</b>	<b>67</b>	<b>10%</b>
<b>G/C Service</b>	<b>49</b>	<b>7%</b>
<b>Usher Genes</b>	<b>100</b>	<b>15%</b>
<b>What do we do?</b>	<b>125</b>	<b>18%</b>

## Question 7

If Deafblind UK secures funding to continue the Usher Project; what further work would you want Deafblind UK's Usher Project to undertake?

In reply to questions 7 and 8, which sought comments, professional people made 51 comments.

Examples.

### **General Practitioner comments**

*"Please continue to remind GPs to look out for Usher Syndrome"*

### **Social Work comments**

*"Continue to provide information for social work departments"*

## Question 8

Any other comments?

### **Deaf organisations comments**

*"I feel the Deaf community is not aware of Usher"*

### **Ophthalmologist comments**

*"It is difficult to keep track of all the conditions we encounter."*

### **General Practitioner comments**

*"I have 800 patients. You do not indicate the prevalence of Usher but I guess I will never come across a case. I'm afraid that I cannot learn about thousands of rare conditions but I now have some information if a case does arise"*

## **8.4 Summary of comments by professional people**

- Almost 52% of those who knew about Usher Syndrome prior to receiving the questionnaire had learned about it from the Usher Syndrome Project.
- Of the 239 people who did not know about Usher Syndrome prior to receiving the questionnaire, 225 were GP's.
- 61% of respondents did not have ready access to information on Usher Syndrome, 66% did not have enough information.
- 31% of respondents thought easy access to information was the single most helpful resource at the time of diagnosis.
- 73% of respondents had enjoyed a direct benefit from the Usher Syndrome Project.

## 9 The views of people who have Usher Syndrome

### 9.1 Purpose

In the final year of the Usher Syndrome Project a questionnaire was distributed to collect evidence regarding achievement of the projects aims.

### 9.2 Methodology

Deafblind UK approached a representative group of 32 people with Usher Syndrome from our existing membership and asked them to complete a Large Print questionnaire. Those people who were unable to complete this questionnaire were interviewed on a one-to-one basis.

The response

- 32 Large Print questionnaires were distributed and 22 replies were received, a response rate of 69%.

#### Question 1

Who diagnosed that you have Usher Syndrome?

<b>GP</b>	<b>3</b>	<b>13%</b>
<b>Audiologist</b>	<b>0</b>	<b>0%</b>
<b>Ophthalmologist</b>	<b>6</b>	<b>25%</b>
<b>Social Worker</b>	<b>2</b>	<b>8%</b>
<b>Other</b>	<b>13</b>	<b>54%</b>

*"I have not received a formal diagnosis"*

#### Question 2

What type of Usher Syndrome do you have?

<b>Type 1</b>	<b>3</b>	<b>13%</b>
<b>Type 2</b>	<b>10</b>	<b>43%</b>
<b>Type 3</b>	<b>0</b>	<b>0%</b>
<b>Other</b>	<b>0</b>	<b>0%</b>
<b>Don't know</b>	<b>10</b>	<b>43%</b>

Question 3

When you were told you had Usher Syndrome, did the person give you information about...?

<b>Deafblind UK, Sense or any other organisation</b>	<b>5</b>	<b>21%</b>
<b>Usher Syndrome</b>	<b>1</b>	<b>4%</b>
<b>Genetics and sight loss</b>	<b>10</b>	<b>25%</b>
<b>Give you NO information</b>	<b>10</b>	<b>42%</b>
<b>Other</b>	<b>2</b>	<b>8%</b>

*“Hospital told me, “You’re registered blind”, that’s all, maybe they said more to my husband”*

Question 4

If you were **not** given any information, where did you look for information?

<b>Library</b>	<b>2</b>	<b>11%</b>
<b>Health Centre</b>	<b>0</b>	<b>0%</b>
<b>Social Work office</b>	<b>1</b>	<b>5%</b>
<b>Deafblind UK</b>	<b>10</b>	<b>53%</b>
<b>Other</b>	<b>6</b>	<b>32%</b>

Question 5

What would have helped you when you were told you had Usher Syndrome?

<b>Information on helpful organisations</b>	<b>14</b>	<b>40%</b>
<b>A contact telephone Helpline number</b>	<b>2</b>	<b>6%</b>
<b>Counselling</b>	<b>6</b>	<b>17%</b>
<b>Information on sight loss</b>	<b>11</b>	<b>31%</b>
<b>Other</b>	<b>2</b>	<b>6%</b>

*“How did I come to have Usher? Can I pass it on to other people?”*

Question 6

Do you have enough information on sight loss?

<b>Yes</b>	<b>13</b>	<b>57%</b>
<b>No</b>	<b>10</b>	<b>43%</b>

Question 7

What have been the benefits to you, if any, from the Usher Syndrome Project?

*"Meeting other people who have Usher Syndrome to share information"*

*"Having access to information on Usher Syndrome that is easy to understand"*

*"I know more about Usher Syndrome so I can explain it to others"*

*"I have more understanding of the genetics of Usher Syndrome"*

*"Some professional people are now more aware of Usher Syndrome"*

*"I feel good because I have learnt to relax and look forward to the future"*

Question 8

If Deafblind UK gets more funding for the Usher Syndrome Project, how should we use it?

<b><i>Make GP's/Hospitals more aware</i></b>	<b>16</b>	<b>25%</b>
<b><i>Provide Guide/communicator training in Deaf clubs</i></b>	<b>8</b>	<b>13%</b>
<b><i>Start support groups in different places</i></b>	<b>14</b>	<b>22%</b>
<b><i>Set up more Guide/communicator or Interpreter services</i></b>	<b>12</b>	<b>19%</b>
<b><i>Help deafblind people get into employment</i></b>	<b>9</b>	<b>14%</b>
<b><i>Other</i></b>	<b>4</b>	<b>6%</b>

*"All of the objectives are important, but local support is crucial"*

*"Make Social Workers aware too!"*

*"Conduct guiding and communication skills training in blind clubs"*

*"Increase awareness of deafblindness in the community"*

*"Set up a training centre for technology and equipment for deafblind people, similar to the Karten Centre in Peterborough"*

*“TV, radio and newspaper advertising to increase awareness of Usher and Deafblind UK among the general public”*

*“More access to information”*

*“I would like someone to read my mail”*

#### Question 9

What is the easiest way for you to get information about Usher Syndrome?

<b>Large Print leaflets</b>	<b>17</b>	<b>50%</b>
<b>Braille/Moon</b>	<b>2</b>	<b>6%</b>
<b>BSL Video</b>	<b>0</b>	<b>0%</b>
<b>One to one person</b>	<b>11</b>	<b>32%</b>
<b>Other</b>	<b>4</b>	<b>12%</b>

### 9.3 Summary of comments by people who have Usher Syndrome

- 42% of people with Usher Syndrome were given **NO** information when they were diagnosed.
- 40% of respondents would have like to have been given information on helpful organisations at the time of diagnosis.
- 53% of respondents approached Deafblind UK for information.
- 50% would like to receive information in Large Print.
- 25% of people who have Usher Syndrome would like to make GPs' and Hospitals more aware.
- 22% thought support groups should be established.

## **10 Conclusion**

The project identified a significant number of people who had Usher Syndrome, yet we remain convinced there are more people who are unidentified.

Without appropriate communication support there is a lack of equal opportunities for people who have a dual impairment. With such small numbers involved there should be little difficulty in funding this support on an on-going basis. The project found the picture was patchy throughout Scotland.

As with all low incidence disabilities there is little incentive for professionals to devote time to learning about it. This compounds the problems for affected individuals, who meet the same lack of knowledge on a daily basis.

There was a general acceptance that the project had served a valuable purpose and that much remained to be done, particularly with regard to creating awareness. A number of volunteers have been trained during the life of the project to deliver awareness training and it is hoped this work will continue.

## **11 Recommendations**

- 1. During their medical training general practitioners should develop an understanding of Usher Syndrome in particular and deafblindness in general. Deafblind awareness training should be delivered by a dual impaired person.**
- 2. Diagnosis of Usher Syndrome can be traumatic. Information on where to seek advice and support should be readily available.**
- 3. Access to employment, training, education, information, and community is limited. Deafblind people are marginalised because of their particular difficulties with communication, information and mobility (Sensing Progress P.38). Dedicated communication support is necessary to begin to improve access. Sensing Progress 1998 saw the provision of a guide/communicator service for dual sensory impaired people as essential (P. 64) <sup>6</sup>**
- 4. The Deaf community should be offered training on how best to interact with members who have Usher syndrome.**
- 5. The Blind community should be offered training on basic tactile communication skills.**
- 6. A research project should be implemented to identify the true incidence of Usher Syndrome.**

# Appendix One – Types of Usher Syndrome

There are 2 main types of Usher Syndrome; a person may be **either**:

Type 1 which mean s/he may be

- **Born profoundly deaf**
- **Develops Retinitis Pigmentosa (RP) between 7-12 years of age**
- **Will have some balance problems when walking**
- **Will often use British Sign Language (BSL) as their mode of communication**

Type 2

- **Born moderately to severely hard of hearing**
- **Develops RP in their late teens to mid twenties**
- **Will not usually have balance problems when walking**
- **Will use speech as their mode of communication**

There is a further 'type' that has been identified, Type 3, which is very rare, and of which there are no recorded incidences in Scotland, the symptoms of Type 3 are:

Type 3

- **Born with no hearing or visual impairment from birth**
- **Develops hearing loss and a visual loss, RP, at an age which varies between individuals**
- **Would have no balance problems when walking**
- **Would use speech as their mode of communication**

## Retinitis Pigmentosa

Retinitis Pigmentosa (RP) is an eye condition that causes a gradual loss of vision. The eye becomes less able to adjust to low light, resulting in night blindness. As RP progresses, the field of vision narrows until only central vision remains. This is called Tunnel Vision. Many people with Usher Syndrome will retain at least **some** central vision for a long time.

## Appendix Two - Expected Number of Usher Syndrome people by Local Authority

Counties and Districts	Population	Expected Number of Deafblind (incidence 2:10,000 and 4:10,000)		Expected Number of Usher (incidence 1:5 of deafblind people)	
Aberdeen	217,260	43	87	9	17
Aberdeenshire	227,430	45	91	9	18
Angus	110,130	22	44	4	9
Argyll and Bute	89,461	18	36	4	7
Clackmannanshire	49,272	10	20	2	4
Dumfries and Galloway	147,178	29	59	6	12
Dundee	153,170	31	61	6	12
East Ayrshire	115,597	23	46	5	9
East Dunbartonshire	109,761	22	44	4	9
East Lothian	91,649	18	37	4	7
East Renfrewshire	90,845	18	36	4	7
Edinburgh	441,620	88	177	18	35
Falkirk	143,040	29	57	6	11
Fife	351,200	70	140	14	28
Glasgow	616,430	123	247	25	49
Highland	208,700	42	83	8	17
Inverclyde	87,100	17	35	3	7
Midlothian	79,910	16	32	3	6
Moray	86,250	17	35	3	7
North Ayrshire	139,520	28	56	6	11
North Lanarkshire	325,940	65	130	13	26
Orkney Islands	19,800	4	8	1	2
Perth and Kinross	132,570	26	53	5	11
Renfrewshire	178,550	36	71	7	14
Scottish Borders	106,100	21	42	4	8
Shetland Isles	22,830	5	9	1	2
South Ayrshire	114,630	23	46	5	9
South Lanarkshire	307,450	61	123	12	25
Stirling	82,750	17	33	3	7
West Dunbartonshire	95,760	19	38	4	8
West Lothian	150,770	30	60	6	12
Western Isles	29,410	6	12	1	2
<b>Total</b>		<b>1022</b>	<b>2048</b>	<b>205</b>	<b>408</b>

# Appendix Three – Evaluation questionnaire

# Usher Syndrome Project Evaluation Questionnaire

Name \_\_\_\_\_  
Organisation \_\_\_\_\_  
Address \_\_\_\_\_  
Telephone \_\_\_\_\_  
Number \_\_\_\_\_ Voice/Text/Fax

1) Before receiving this letter, did you know about Usher Syndrome?

Yes  No

a) If YES, from where did you find out about Usher Syndrome?

Deafblind UK Usher Project  Usher Roadshows  Publicity material   
Other (please specify): \_\_\_\_\_

2) Do you have ready access to information about Usher Syndrome?

Yes  No

a) If YES, in which format is it available?

Normal Print  Moon  BSL Signed Video   
Large Print  Braille  Audio Tape   
Other (please specify): \_\_\_\_\_

b) If NO, where would you try to find information on Usher Syndrome?

Deafblind UK  Blind Club/Society  ENT Department   
Sense  Deaf Club/Society  Eye Department   
Health Centre  Social Work  Audiology   
Other (please specify): \_\_\_\_\_

3) Do you know anyone who may have undiagnosed Usher Syndrome? (People who have been deaf or hard of hearing since birth and developed RP in their 20's)  
If so, please specify how many would fall into this category:

4) What would help you at the time of Usher Syndrome diagnosis?

- Easy access to information       Contact with Usher organisations       Leaflets   
Communication support       Appropriate support   
Other (please specify): \_\_\_\_\_

5) What have been the benefits to you, if any, from Deafblind UK's Usher Syndrome Project?

- Easily available Information       Training       Awareness   
Advice/support       None   
Other (please specify): \_\_\_\_\_

6) Do you think you have enough information on all aspects of Usher Syndrome?

- Yes       No

a) Would you like information? Please tick as many as needed:

- Helpful organisations       Training opportunities       Usher Syndrome Genetics   
Usher Syndrome Project/Deafblind UK       Guide communicator service       What do we do?

7) If Deafblind UK secures funding to continue the Usher Project, what further work would you want Deafblind UK's Usher Syndrome Project to undertake?

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8) Any other comments:

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**Appendix Four – Evaluation questionnaire for people who have Usher Syndrome**

# Usher Project Evaluation Questionnaire

1. Who diagnosed that you have Usher?

- GP       Audiologist   
Ophthalmologist       Social Worker   
Other

2. What type of Usher do you have?

- Type 1       Type 2       Type 3   
Other       Don't know

3. When you were told you had Usher did the person?

- Give you information about Deafblind UK Sense or any other organisations   
Give you leaflets about Usher   
Talk to you about genetics or sight loss   
No information was given to me

4. If you were **not** given information, where did you look for information?

- |                    |                          |               |                          |
|--------------------|--------------------------|---------------|--------------------------|
| Library            | <input type="checkbox"/> | Health Centre | <input type="checkbox"/> |
| Social Work office | <input type="checkbox"/> | Deafblind UK  | <input type="checkbox"/> |
| Other              | <input type="checkbox"/> |               |                          |

5. What would have helped you when you were told you had Usher?

- Information on helpful organisations
- A contact telephone number for a helpline
- Counselling
- Information on sight loss
- Other

6. Do you now have enough information about Usher?

- Yes  No

7. What have been the benefits to you if any from the Usher Project?

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8. If Deafblind UK gets more funding for the Usher Project how should we use it?

- Make GPs/Hospitals more aware
- Provide Guide/communicator training in Deaf clubs
- Start support groups in different places
- Set up more Guide/communicator or Interpreter services
- Help deafblind people get into employment

Other, please specify

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9. What is the easiest way for you to get information about Usher?

- Large Print leaflets
- Braille/Moon
- BSL Video
- One to one person
- Other

## Appendix - Bibliography

<sup>1</sup> Vernon, M, 1976. Usher Syndrome: a genetic disease involving congenital deafness and progressive loss of vision due to Retinitis Pigmentosa. Proc. Seminar Usher Syndrome: Rochester N.Y., Rochester School for the Deaf.

<sup>2</sup> Deafblind Service Liaison Group. Breaking Through Report September 1988

<sup>3</sup> Signposts, Social Services Inspectorate 1989

<sup>4</sup> Department of Health Guidelines, Think Dual Sensory, 1995

<sup>5</sup> Population figures taken from General Register Office for Scotland estimated population of Scotland at 30<sup>th</sup> June 1996

<sup>6</sup> Sensing Progress, Social Work Services Inspectorate 1998

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