Thank you for agreeing to complete this short questionnaire. The questionnaire is separated into three sections. The first section asks general information about you. The second section asks information specific to your Fabry and the third asks about depression. The questionnaire will take approximately 5 minutes. Please mark your response with an ‘X’ or the answer in numbers or words where indicated. If you have any questions please phone your Fabry centre.

**SECTION ONE:**

**Q1** Your age in years

**Q2** Your gender

- Male
- Female

**Q3** Where do you live in the UK?

- North East England
- North West England
- South East England
- South West England
- London
- Central England
- Wales
- Scotland
- Not disclosed/Unknown
Q5 What is the highest level of education you have achieved?

- No Qualifications
- CSE grade 2-5/GCSE grades D-G or equivalent
- CSE grade 1/O-level/GCSE grades A-C or equivalent
- A-level, AS-level or equivalent
- Degree/postgraduate qualification or equivalent
- Other (Write in)
- Not disclosed/Unknown

Q6 Employment status –
Which of these descriptions best describes your situation (in the last 7 days)?

- "Full-time paid employee (30 or more hours a week)"
- "Part-time paid employee (under 30 hours a week)"
- "Full-time self-employed"
- "Part-time self-employed"
- "Unemployed and seeking work"
- "Full time education"
- "On a government scheme for employment training"
- "Temporarily sick/disabled"
- "Permanently sick/disabled"
- "Looking after home/family"
- "Wholly retired"
- "Other (please specify by writing in)"
- Not disclosed/Unknown

Q7 Income –
Which of these descriptions comes closest to how you feel about your household’s income (in the last 7 days)?

- "Living comfortably on present income"
- "Coping on present income"
- "Finding it difficult on present income"
- "Finding it very difficult on present income"
- Not disclosed/Unknown
**SECTION TWO:**

**Q8** What age (in years) do you remember first experiencing Fabry symptoms?

<table>
<thead>
<tr>
<th>Age</th>
<th>Not disclosed/Unknown</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Q9** If you have children, how many are diagnosed with Fabry?

<table>
<thead>
<tr>
<th>I don’t have any children</th>
<th>I have _________ (number) of children diagnosed with Fabry</th>
<th>Not disclosed/Unknown</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Q10** How many people in your family do you know have been diagnosed with Fabry? *(Including grand parents, parents, aunties, uncles, cousins, brothers, sisters)*

<table>
<thead>
<tr>
<th>I have _________ (number) of family diagnosed with Fabry</th>
<th>Not disclosed/Unknown</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Q11** How much do you think your Fabry symptoms interfere with your life?

<table>
<thead>
<tr>
<th>Not at all</th>
<th>Slightly</th>
<th>Moderately</th>
<th>Quite a bit</th>
<th>Extremely</th>
<th>Not disclosed/Unknown</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Q12** Please tick any Fabry symptom which interferes with your life? *(Interferes also refers to the words ‘gets in the way’, ‘hinders’, ‘obstructs’)*

- Acroparesthesia (pain in hands and feet)
- Angiokeratoma (skin rash)
- Abdominal (pain, diarrhoea)
- Anhidrosis (not sweating normally)
- Cardiac/Heart symptoms (irregular heart beat, heart attack, congestion)
- Cerebrovascular/Brain (stroke, migraine)
- Kidney/urinary problems (protein in urine, dialysis, kidney transplant)
- Ophthalmologic/Eye problems
- No Fabry symptom interferes with my life
Q13  Do you have any other medical condition/s that interferes with your life (in addition to Fabry disease)? *(for example, diabetes, hayfever, asthma)*

If yes, please give details:

No, I have no other medical conditions  
Not disclosed/Unknown

Q14  Do you receive Enzyme Replacement Therapy at the moment?

Yes  If Yes, please answer question 14.1 and 14.2
No  If No, please move to question 15
Not disclosed/Unknown

Q14.1 How long have you been receiving Enzyme Replacement Therapy?

Less than 6 months
6-12 months
12-18 months
18 months – 2 years
Longer than 2 years
Not disclosed/Unknown

Q14.2 Since starting Enzyme Replacement Therapy do you think your Fabry symptoms are . . . . .

Much better
Somewhat better
About the same
Somewhat worse
Much worse
Not disclosed/Unknown

Q15  How much do you think Fabry Treatments interfere with your life?

Not at all
Slightly
Moderate
Quite a bit
Extremely
Not disclosed/Unknown
SECTION THREE:

Q16 Have you ever been told by a doctor you have depression?

Yes ☐ No ☐ Not disclosed/Unknown ☐

Q17 Has a doctor told you that you have depression at the moment?

Yes ☐ No ☐ Not disclosed/Unknown ☐

Q18 Do you take any medication for depression at the moment?

Yes ☐ No ☐ Not disclosed/Unknown ☐

Q19 Have you been referred to a counsellor/ psychologist/ psychiatrist for depression in the past six months?

Yes ☐ No ☐ Not disclosed/Unknown ☐

Please now turn over this page to complete the short statements relating to how you have felt or behaved in the last week.

When you have completed the questionnaires please take time to check that you have not missed any questions by mistake.

Please keep the information sheet for your records.

Remember, if you have any questions about this study you can contact your Fabry centre or any of the support groups on the information sheet.

Please return this questionnaire in the pre-paid envelope provided as soon as possible once it is completed.
Questionnaire Two: CES- Depression Scale

INSTRUCTIONS: Using the scale below, please circle the number at each statement which best describes how often you felt or behaved this way DURING THE PAST WEEK

1 = Rarely or none of the time (less than 1 day)  
2 = Some or a little or the time (1-2 days)  
3 = Occasionally or a moderate amount of time (3-4 days)  
4 = Most or all of the time (5-7 days)

DURING THE PAST WEEK,
1. I was bothered by things that usually don't bother me  
2. I did not feel like eating; my appetite was poor  
3. I felt that I could not shake off the blues even with help from my family or friends.  
4. I felt that I was just as good as other people.  
5. I had trouble keeping my mind on what I was doing  
6. I felt depressed  
7. I felt that everything I did was an effort  
8. I felt hopeful about the future  
9. I thought my life had been a failure  
10. I felt fearful  
11. My sleep was restless  
12. I was happy  
13. I talked less than usual  
14. I felt lonely  
15. People were unfriendly  
16. I enjoyed life  
17. I had crying spells  
18. I felt sad  
19. I felt that people dislike me  
20. I could not ‘get going’

THANK YOU FOR YOUR TIME