This is not a scientific survey. All the information on this survey is published in good faith and for general information purpose only. While every caution has been taken to provide the most accurate information and honest analysis, SIP does not make any warranties about the completeness, reliability and accuracy of this information. Any action you take upon the information on survey is strictly at your own risk and SIP will not be liable for any losses and damages in connection with its use.
### Results of Data Collected in Graph Form

#### Age of Subjects
![Bar chart showing age distribution of subjects.](image)

#### Sample Size
<table>
<thead>
<tr>
<th>Gender</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female</td>
<td>75</td>
</tr>
<tr>
<td>Male</td>
<td>25</td>
</tr>
<tr>
<td>Total</td>
<td>100</td>
</tr>
</tbody>
</table>

#### How many other family members do have Stickler syndrome?
![Bar chart showing family member count.](image)

*About 80% said they have more family members with the syndrome.*

#### Effect of Retinal Detachment
![Bar chart showing retinal detachment effect.](image)

*47% said they had a retinal detachment.*

**NOTE:** N/A column includes people who had no effect or did not match any of the other four listed criteria.

**NOTE:** unclear answers or if the person did not know the answer to the question, they were placed in the Not Applicable (N/A) category for measurement purposes.
**Age When Retinal Detachment Occurred**

NOTE: unclear answers or if the person did not experience a retinal detachment, their response was placed in the Not Applicable (N/A) category for measurement purposes.

**Age When Cataract Removed**

NOTE: unclear answers or if the person did not experience cataract(s), their response was placed in the Not Applicable (N/A) category for measurement purposes.

*89% surveyed said they are nearsighted (prescriptions mostly between -12 and -8).*
NOTE: For both Graphs on this page;

Unknown = person did not know their prescription.

N/A = unclear responses or no response given.
Effect of Glaucoma

**NOTE:** N/A column includes unclear answers and the people who did not experience Glaucoma.

*19% said they had Glaucoma in at least one eye.*

Age When Stiff Joints Noticed

**NOTE:** N/A column includes unclear answers and the people who did not list an age when they noticed stiff joints.

*84% noticed stiff joints (mostly between 0 and 29 years old).*

Extent within the stiffness affects daily life

**NOTE:** On a scale of 1-10 (1 is minimum and 10 is maximum).

N/A = No affect to daily life or unclear answers.
### Stiff joints

<table>
<thead>
<tr>
<th>Category</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>N/A</td>
<td>29</td>
</tr>
<tr>
<td>Other</td>
<td>25</td>
</tr>
<tr>
<td>Fingers</td>
<td>40</td>
</tr>
<tr>
<td>Hands</td>
<td>35</td>
</tr>
<tr>
<td>Ankles</td>
<td>42</td>
</tr>
<tr>
<td>Knees</td>
<td>63</td>
</tr>
<tr>
<td>Hips</td>
<td>55</td>
</tr>
</tbody>
</table>

NOTE: N/A column includes unclear answers and the people who did not experience stiff joints or they did not fit in one of the six categories.

### Age when noticed hypermobile joints

*77% noticed hypermobile joints (mostly between 0 and 19 years old).*

### Extent within the hypermobility affects daily life

*30% reported having knock-knees*
**Effect of the deterioration of the cochlear nerve**

*19% reported having cochlear nerve deterioration.*

27% had glue ear (mostly both ears).

<table>
<thead>
<tr>
<th>Deafness</th>
<th>Hearing loss</th>
<th>N/A</th>
</tr>
</thead>
<tbody>
<tr>
<td>2</td>
<td>17</td>
<td>81</td>
</tr>
</tbody>
</table>

**Reach of the cleft lip and palate**

*45% had a cleft lip and palate.*

<table>
<thead>
<tr>
<th>Uvula</th>
<th>Palate</th>
<th>Jaw</th>
<th>Upper lip</th>
<th>Unknown</th>
<th>N/A</th>
</tr>
</thead>
<tbody>
<tr>
<td>6</td>
<td>14</td>
<td>6</td>
<td>0</td>
<td>0</td>
<td>43</td>
</tr>
<tr>
<td>22</td>
<td>28</td>
<td>2</td>
<td>1</td>
<td>2</td>
<td>55</td>
</tr>
</tbody>
</table>

**Extent within the scoliosis affects daily life**

<table>
<thead>
<tr>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th>N/A</th>
</tr>
</thead>
<tbody>
<tr>
<td>8</td>
<td>7</td>
<td>3</td>
<td>1</td>
<td>5</td>
<td>2</td>
<td>4</td>
<td>3</td>
<td>0</td>
<td>1</td>
<td>66</td>
</tr>
</tbody>
</table>

NOTE: Unknown = person did not know the cleft reach

N/A = unclear responses, no response given or the person did not have a cleft lip or palate symptom.

NOTE: On a scale of 1-10 (1 is minimum and 10 is maximum).

N/A = No affect to daily life or unclear answers.
82% reported they had facial features (mostly a flat nasal bridge and a small nose).

41% reported micrognathia (where the jaw is undersized).
Some results of Survey (population of 100 respondents)

81% > more family members with the syndrome.
89% > nearsighted (mostly between -12 and -8).
47% > retinal detachment.
52% > cataract.
19% > glaucoma.
84% > stiff joints (mostly noticed between 0 and 29 years old)
77% > hypermobile joints (mostly noticed between 0 and 19 years old)
70% > knock-knees
41% > micrognathia (where the jaw is undersized)
45% > cleft lip and palate
27% > glue ear (mostly both ears)
19% > cochlear nerve deterioration
37% > scoliosis.
82% > facial features (mostly a flat nasal bridge and a small nose)

The Stickler Involved People’s (SIP) Board of Directors is grateful to Eline van Oostrum and all the participants of the Survey. This information is very interesting and, as promised, being shared with those interested in Stickler syndrome. We appreciate all the efforts involved in gathering, compiling and posting the data. Thanks everyone.