

ELINE VAN OOSTRUM'S STICKLER SYNDROME SURVEY RESULTS APRIL, 2013

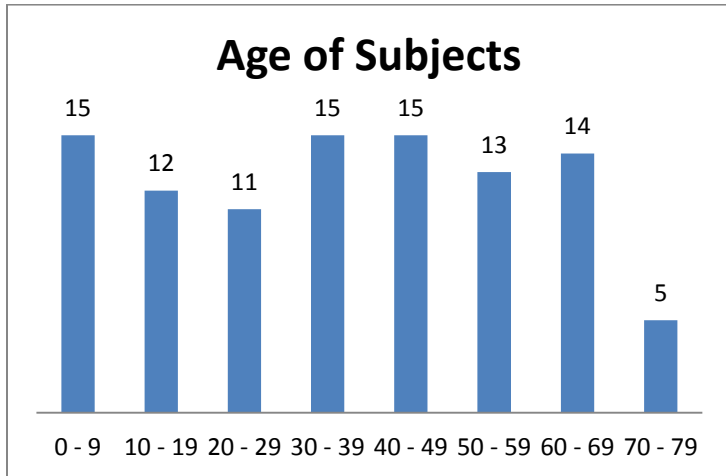


This is not a scientific survey. All the information on this survey is published in good faith and for general information purpose only. While every caution has been taken to provide the most accurate information and honest analysis, SIP does not make any warranties about the completeness, reliability 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.

Survey created to fulfill
her Senior High School
Project. Score: A

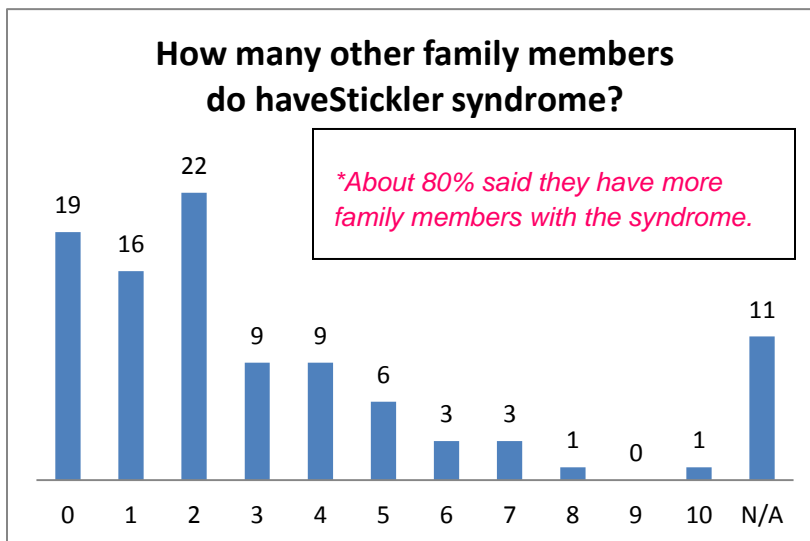
Edited by Rick Bishop for SIP

Results of Data Collected in Graph Form

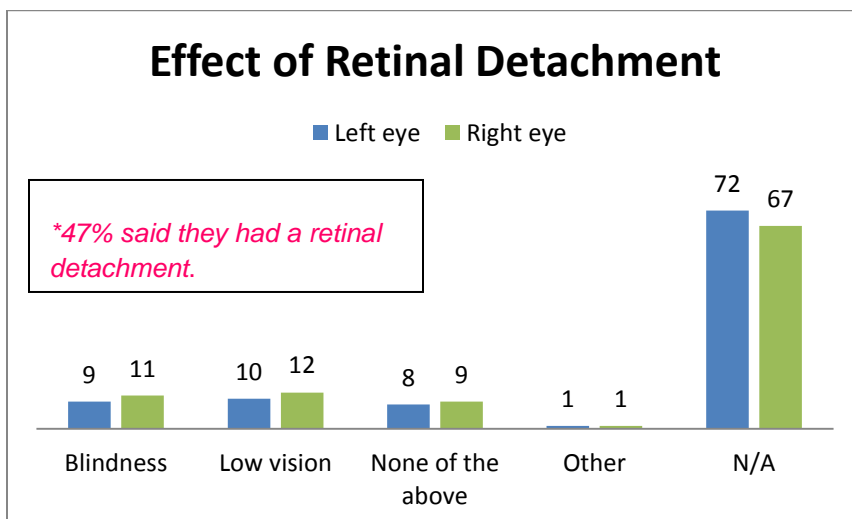


Sample Size

| Gender | |
|--------|-----|
| Female | 75 |
| Male | 25 |
| Total | 100 |

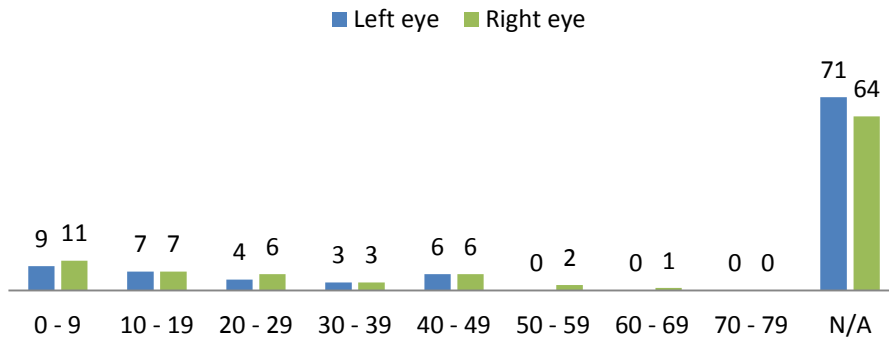


NOTE: unclear answers or if the person did not know the answer to the question, they were placed in the Not Applicable (N/A) category for measurement purposes.



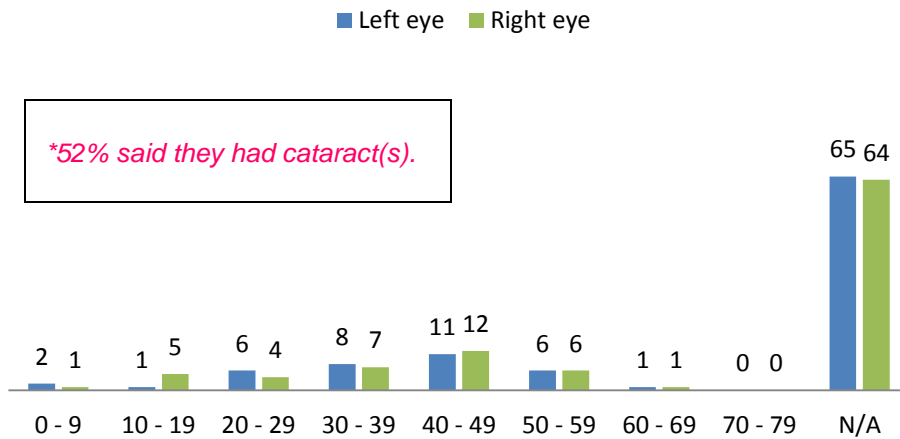
NOTE: N/A column includes people who had no effect or did not match any of the other four listed criteria.

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

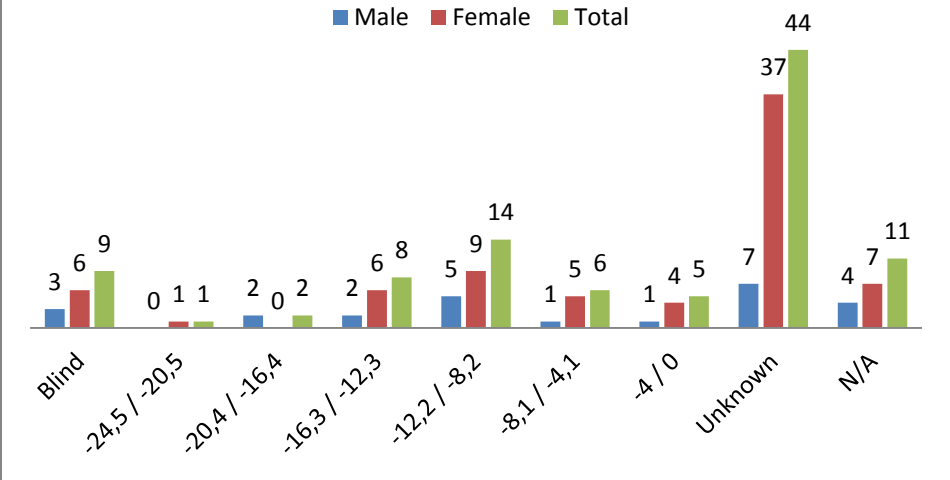


**52% said they had cataract(s).*

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).*

Prescription of the Left Eye

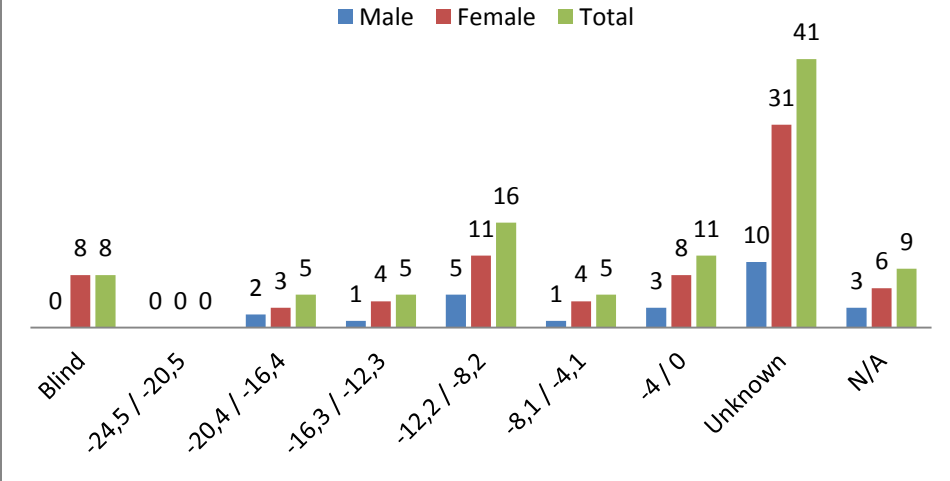


NOTE: For both Graphs on this page;

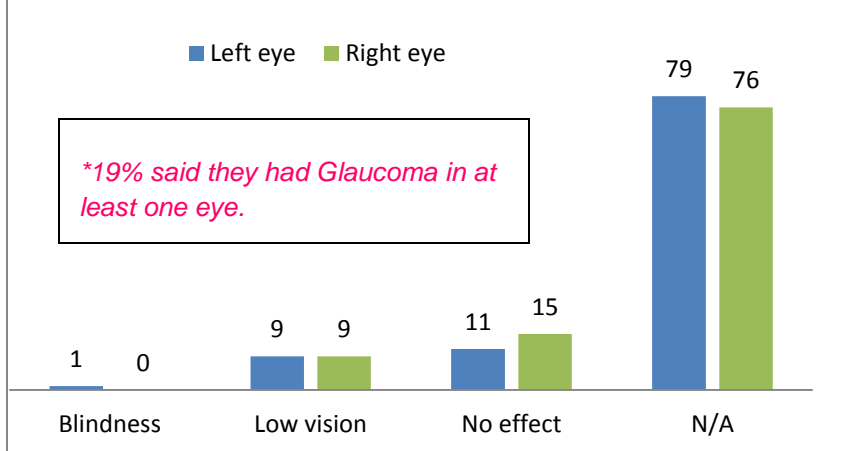
Unknown = person did not know their prescription.

N/A = unclear responses or no response given.

Prescription of the Right Eye

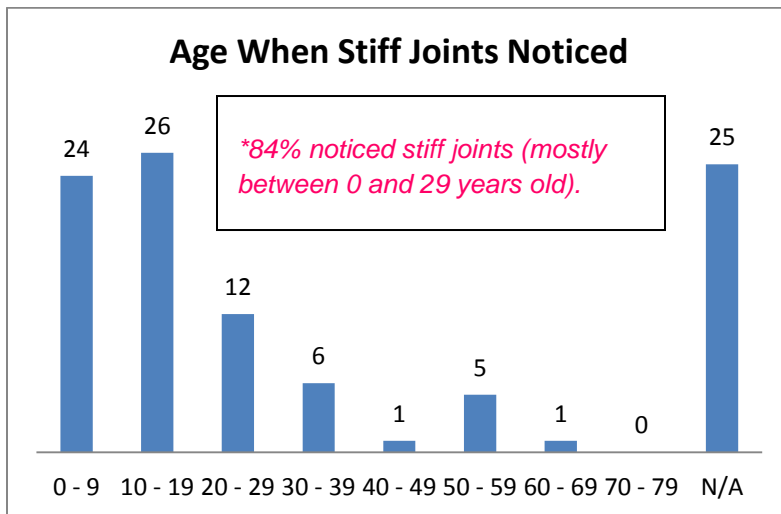


Effect of Glaucoma



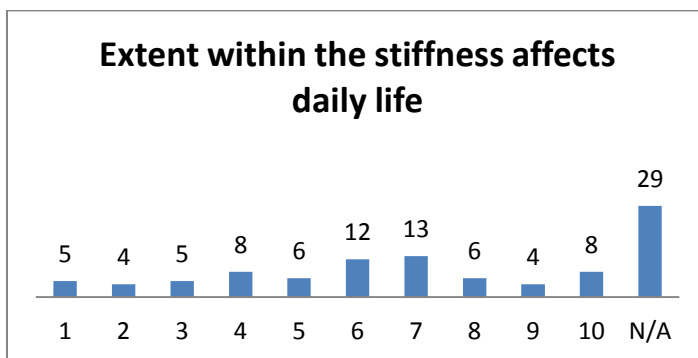
NOTE: N/A column includes unclear answers and the people who did not experience Glaucoma.

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.

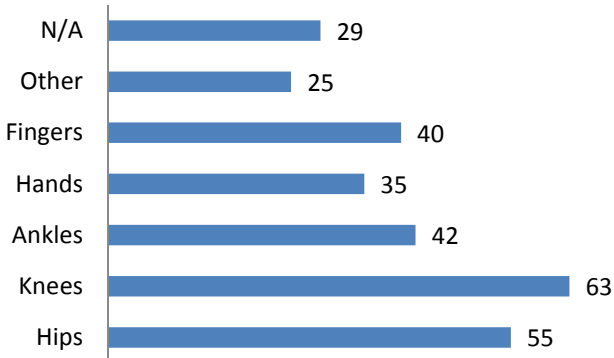
Extent within the stiffness affects daily life



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

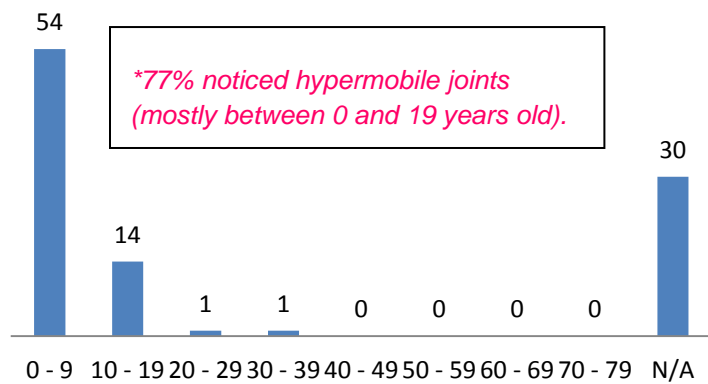
N/A = No affect to daily life or unclear answers.

Stiff joints



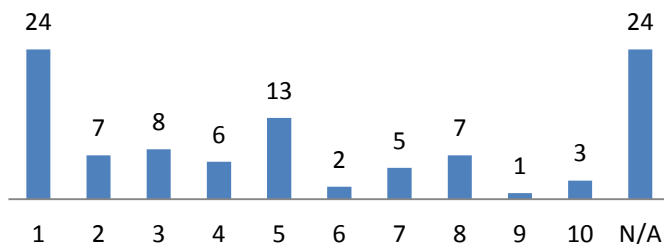
NOTE: N/A column includes unclear answers and the people who did not experience stiff joints or they did not fit in one of the six categories.

Age when noticed hypermobile joints



NOTE: N/A column includes unclear answers, those that did not have hypermobile joints and the people who did not list an age when they noticed hypermobile joints.

Extent within the hypermobility affects daily life



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

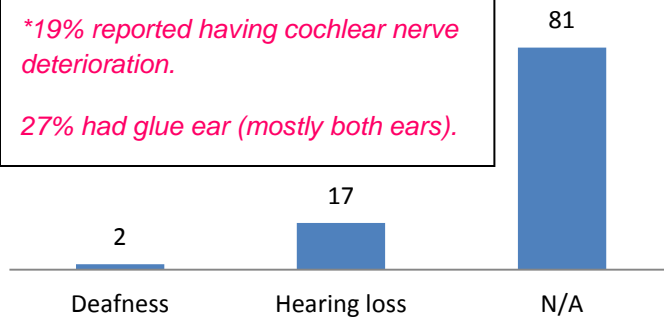
N/A = No affect to daily life or unclear answers.

**30% reported having knock-knees*

Effect of the deterioration of the cochlear nerve

**19% reported having cochlear nerve deterioration.*

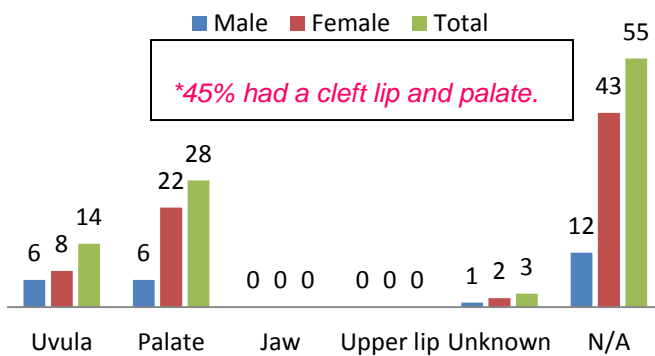
27% had glue ear (mostly both ears).



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

Reach of the cleft lip and palate

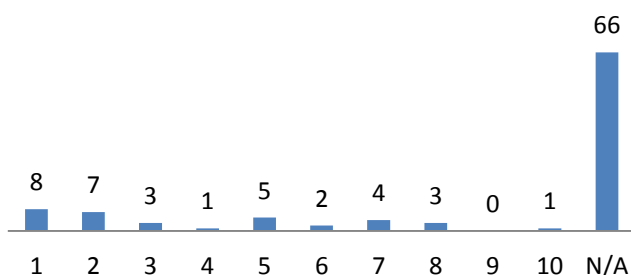
**45% had a cleft lip and palate.*



NOTE: Unknown = person did not know the cleft reach

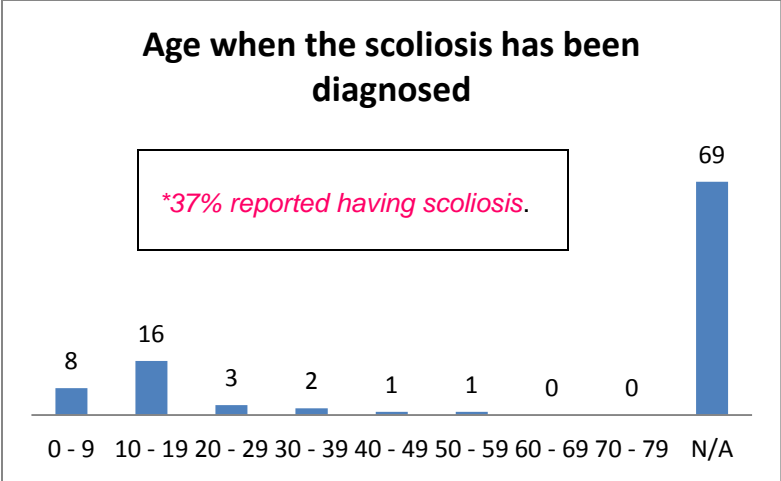
N/A = unclear responses, no response given or the person did not have a cleft lip or palate symptom.

Extent within the scoliosis affects daily life

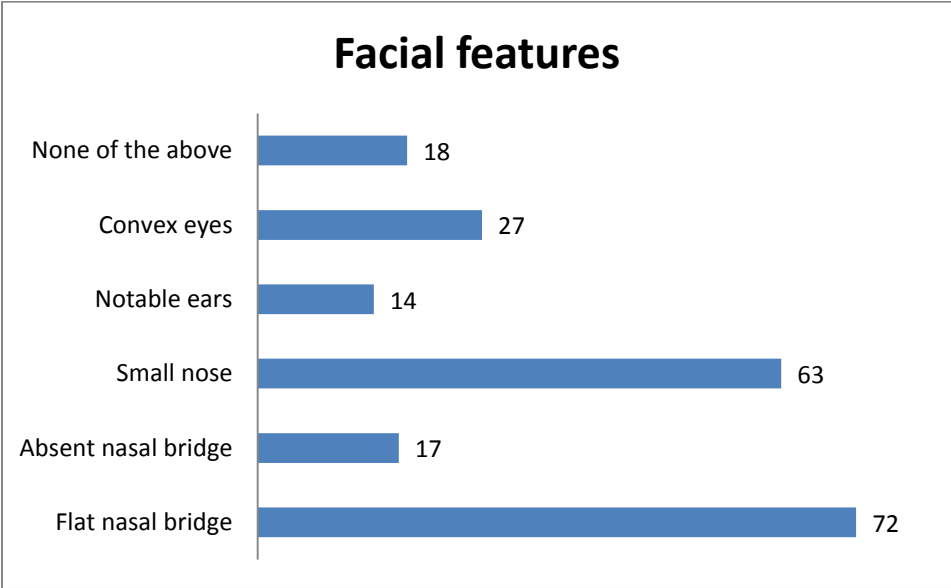


NOTE: On a scale of 1-10 (1 is minimum and 10 is maximum).

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



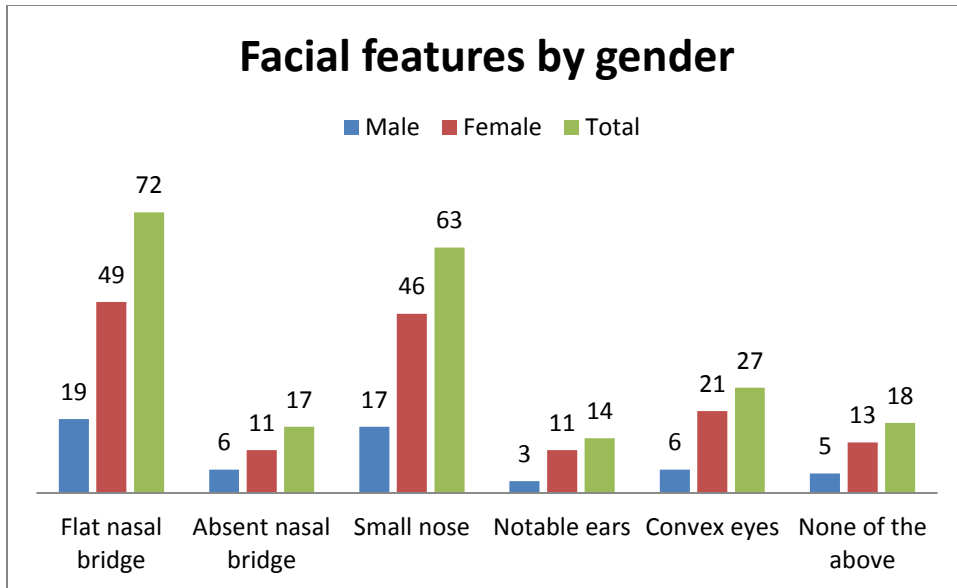
NOTE: N/A column includes unclear answers, those that did not have scoliosis and the people who did not list an age when they noticed scoliosis.



NOTE: 'none of the above' column includes unclear answers and the people who were not familiar with any of the six categories.

82% reported they had facial features (mostly a flat nasal bridge and a small nose).

41% reported micrognathia (where the jaw is undersized).



NOTE: 'none of the above' column includes unclear answers and the people who were not familiar with any of the six categories.

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.