2012 Patient Survey

351 participants
(In 2011: 269 participants)

New participating country in 2012: Poland
2012 Patient Survey

About the participants

- Poland
- Germany
- Italy
- France
- UK
- Spain

- Other relative
- Guardian of a patient
- Parent of a patient
- A patient
2012 Patient Survey

Current age of the patients

Younger patient: 5 years old (Italy) / Older patient: 78 years old (UK)

Mean current age of the patients in Europe: 33 years old

<table>
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<tr>
<th>Countries</th>
<th>Poland</th>
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<th>France</th>
<th>UK</th>
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<tbody>
<tr>
<td>Mean current age of the patients</td>
<td>38 years old</td>
<td>36 years old</td>
<td>22 years old</td>
<td>35 years old</td>
<td>40 years old</td>
<td>28 years old</td>
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</tbody>
</table>
What were your (her/his) first symptom(s)?

- Amenorhea (9.6%)
- Difficulties getting pregnant (7.7%)
- Miscarriages (4.6%)
- Behavioural changes (8.3%)
- Mood changes (8.0%)
- Movement disorders (4.5%)
- Difficulty writing (11.5%)
- Difficulties at school/work (15.8%)
- Jaundice (1.7%)
- Other hepatic symptoms (13.2%)
- Anemia (0.8%)
- Weariness (0.7%)
- Growth problems (4.0%)

Others: Family screening, dermatological problems, speech difficulties…
How old were you (or the patient) when the first medical symptoms appeared?

Mean age in Europe: 16 years old

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<tr>
<td>Mean age of the patients</td>
<td>26 years old</td>
<td>18 years old</td>
<td>8 years old</td>
<td>16 years old</td>
<td>17 years old</td>
<td>15 years old</td>
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How old were you (or the patient) when you received a confirmed diagnosis of WD?

Mean age in Europe: 15 years old

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Could you state approximately the time between your (her/his) first symptoms and the diagnosis of Wilson disease?

In Europe:

- <3 months: 3%
- Between 3 and 6 months: 7%
- Between 6 months and 1 year: 22%
- Between 1 and 3 years: 19%
- Between 3 and 5 years: 10%
- Between 5 and 10 years: 17%
- More than 10 years: 22%
What was the medical specialty of the first doctor you (or the patient) consulted for these symptoms?

**Others:** Dermatologist, Endocrinologist, Hematologist, Oncologist, Physiotherapist, Pulmonologist, Psychologist.
2012 Patient Survey

Have you (or the patient) been misdiagnosed?

Poland | Germany | Italy | France | UK | Spain

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<tr>
<th>No</th>
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Have you (or the patient) been misdiagnosed?

If yes, please state the disorder:

Others: Endocrinological problems, Hypertension, Leukemia, Leukopenia, Mononucleosis, Multiple Sclerosis…
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Currently, how often do you (or the patient) see your specialist?

In Europe
Currently, how often do you (or the patient) have a blood test?

In Europe
Currently, how often do you (or the patient) have a liver ultrasonography?

In Europe
Currently, how many times a day do you (or the patient) take your medication for WD?

In Europe:

- Once a day: 43.5%
- Twice a day: 8.2%
- 3 times a day: 5.6%
- More than 3 times a day: 2.7%
- Other: 40.0%
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What was your (her/his) initial treatment for Wilson disease?

What is your (her/his) current treatment for Wilson disease?
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Have you (or the patient) changed your medication between the time of diagnosis and now?

If yes, please specify why:

Others:
- Change of dosage
- Liver transplantation
- Pregnancy
How was your (her/his) treatment started?

- Immediately full dosage
- Progressively
- Don't know

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In your country, do you (or the patient) have difficulties getting reimbursed for your treatment?
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Are you (or the patient) in a programme of rehabilitation?

If yes:

If no:
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Do you (or the patient) use any forms of complementary medicine?

If yes:

If you (or the patient) use any forms of complementary medicine?
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Before you answered this survey, had you heard about EuroWilson?

In 2011:

- Poland: 100% Yes, 0% No
- Germany: 80% Yes, 20% No
- Italy: 90% Yes, 10% No
- France: 90% Yes, 10% No
- UK: 100% Yes, 0% No
- Spain: 90% Yes, 10% No

Don't Know: 0%
In your opinion, what should be the most important mission of EuroWilson?