Longterm Followup of Quality of Life in Patients with Cryopyrin-associated Periodic Syndrome Treated with Canakinumab, an Anti-interleukin 1 β Monoclonal Antibody

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To the Editor:

Cryopyrin-associated periodic syndrome (CAPS) is an inherited autoinflammatory disorder that comprises a clinical spectrum of 3 distinct phenotypes increasing in severity: familial cold autoinflammatory syndrome, Muckle-Wells syndrome (MWS), and chronic infantile neurological cutaneous and articular syndrome (CINCA). Urticarial rash, fever, arthralgia, and intense fatigue are the main clinical signs. CINCA is one of our most important observations; no patients were out of work during the followup. The gain in vitality scores permitted them to enjoy a social life after work and physical activity, which were impossible without treatment.

One study compared HRQOL in patients treated first with anakinra and then with canakinumab, but the authors did not reveal significant difference between treatments.

Canakinumab had proven its efficacy and safety in treatment of patients with CAPS with rapid clinical and biological remission after the first dose of treatment. We have shown that canakinumab had not only a sustained effect on quality of life, but also allowed dramatic changes in social and work lives. The good tolerance of the injections and the long interval between doses of canakinumab were real benefits for patients requiring lifelong treatment.

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REFERENCES

Table 1. Changes in quality of life. Values are expressed in mean ± SD.

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<th>General Population</th>
<th>Baseline D2304/2306, n = 7</th>
<th>End D2306, n = 7</th>
<th>Last Visit, n = 7</th>
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<tr>
<td>FACIT-F</td>
<td>43.5</td>
<td>25.1 ± 11.3</td>
<td>42.6 ± 5.8*</td>
<td>42.3 ± 6.9*</td>
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<td>SF-36 PCS</td>
<td>50</td>
<td>37.7 ± 4.8</td>
<td>49.7 ± 4.9*</td>
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<tr>
<td>SF-36 MCS</td>
<td>50</td>
<td>34.1 ± 11.4</td>
<td>44.1 ± 9</td>
<td>43.9 ± 8.7</td>
</tr>
<tr>
<td>HAQ</td>
<td>—</td>
<td>0.64 ± 0.73</td>
<td>0.32 ± 0.56</td>
<td>0.52 ± 0.83</td>
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* p value < 0.05. FACIT-F: Functional Assessment of Chronic Illness Therapy-Fatigue; SF-36: Medical Outcomes Study Short Form-36 survey; PCS: physical component summary; MCS: mental component summary; HAQ: Health Assessment Questionnaire; D2304/2306: canakinumab/CAPS study.

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Figure 1. Evolution of mean scores in the 8 domains of Medical Outcomes Study Short Form-36 survey (SF-36) questionnaires. PCS: physical component summary; MCS: mental component summary; PF: physical functioning; RP: role physical; BP: body pain; GH: general health; VT: vitality; SF: social functioning; RE: role emotional; MH: mental health; End D 2306: End values, canakinumab/CAPS study (June 2012).