

# Health-related quality of life in children with newly diagnosed immune thrombocytopenia

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## **Supplemental Data**

### **Supplemental methods**

#### **Bleeding severity**

Bleeding severity was scored using a modified version of the Buchanan bleeding score, published by Bennett et al.<sup>13,14</sup>, ranging from 0 (no bleeding) to 5 (life-threatening or fatal). At each timepoint, the highest bleeding score since the last study visit was noted by the patients' pediatrician in a webbased case record form (CRF). Since bleeding scores were reported as highest bleeding score since the last visit and HRQoL scores were reported regarding the preceding week only, bleeding tendency at time of assessing HRQoL did not necessarily match with bleeding scores in the CRF, especially at time points later than 1 month after diagnosis. For this reason, analysis regarding bleeding tendency was limited to diagnosis, 1 week and 1 month after diagnosis.

#### **HRQoL questionnaires**

##### ***Pediatric Quality of Life Inventory (PedsQL)<sup>TM</sup>***

This study was carried out using the PedsQL<sup>TM</sup> Generic Core Scales (Dutch acute version), developed by Dr. James W. Varni.<sup>18-23</sup> We used the PedsQL<sup>TM</sup> self report questionnaire versions starting from age of 7 as well as the paired parent proxy questionnaires for all children aged 2 years and older. Total scale scores, psychosocial health summary scores and physical health summary scores were computed according to the manual of the PedsQL<sup>TM</sup>. If more than 50% of items in the scale were missing, scale scores could not be computed. PedsQL<sup>TM</sup> proxy report reference data were available for children aged 5-7 years and PedsQL<sup>TM</sup> child self-report reference data were available for children aged 8-18 years,

whereas our ITP study included children aged 3 months-16 years. To be able to compare our ITP patients with the reference group, analysis was limited to children aged 5-7 years for PedsQL proxy report data and to children aged 8-16 years in the ITP group as well as the reference data group for PedsQL child self-report data.

### ***Kid's ITP Tools (KIT)***

The disease specific KIT was developed by Barnard and colleagues,<sup>24</sup> and further refined and validated by Klaassen and Blanchette and their colleagues.<sup>25,26</sup> The KIT contains disease related questions regarding, for example, fear of bleeding, being annoyed by restrictions of activities and feeling uncomfortable about bruises. In close collaboration with the Canadian study group we developed a Dutch version of the KIT by formal translation, back-translation and cross-cultural validation. The KIT consists of a child self-report version that can be completed by children aged 7 years and older, a parent proxy report in which parents of children aged 2-18 years can answer questions regarding HRQoL of their child and a parent self-report that is completed by parents to assess HRQoL of parents themselves. The items of each component are aggregated into a single overall score ranging from 0 (worst) to 100 (best).