Appendices

Procedure and inclusion of respondents
PROCEDURE AND INCLUSION OF RESPONDENTS

Asthma
All 201 parents of children diagnosed with asthma, who had visited the pediatric pulmonology outpatient clinic of the Emma Children’s Hospital in 2005, were approached by mail. A reminder letter was sent to non-responders in order to increase response. A total of 99 questionnaires were returned, of which 97 (48%) could be used in this study. The families who did not participate did not differ from participating families with respect to age of the child with asthma (T-test, p<0.1). The gender of children of non-participants did differ from that of participants, as in the non-participants group there were relatively more boys with asthma and less girls, compared to the participants group (Binomial test, p<0.1).

Survivors of a brain tumor
All parents of children who had completed treatment for a brain tumor at the Emma Children’s Hospital at least one year ago (n=63), were invited to participate in the Care-study by mail. Non-responders were contacted by phone, and a reminder letter was sent in order to increase response. Forty-three parents (68%) participated. The families who did not participate did not differ from the participating families with respect to age (t-test, p<0.1) or gender (Binomial test, p<0.1) of the children.

Diabetes
The diabetes group includes parents of all diabetes patients monitored in the Emma Children’s hospital. A total of 56 families were eligible for this study. Non-responders were contacted by phone to increase participation. Twenty-four (43%) questionnaires were returned. The families who did not participate did not differ from the participating families with respect to age (t-test, p<0.1) or gender (Binomial test, p<0.1) of the children with diabetes.

Down syndrome
A cohort of Dutch children born with Down syndrome between 1999 and 2001 was included. This cohort was studied and described by Trotsenburg et al. Initially, this cohort consisted of 196 children. Of this cohort, 19 were lost to follow up due to death of the children and because of unknown addresses. For the Care-project we approached 177 parents. A reminder letter was send to non-responders to increase participation. The final sample included 103 (58%) returned questionnaires. Non-participants did not differ from participants with respect to age or gender distribution of the children with Down-syndrome (T-test; Binomial test, p<0.1).

Duchenne muscular dystrophy
Parents of children with Duchenne were all members of the Dutch department of the Duchenne Parent Project. All parents (n=125) were invited to participate by a letter from the president of the Duchenne Parent Project. The 76 (61%) parents who filled out a reply form
received a questionnaire. A reminder letter was sent to non-responders in order to increase participation. Sixty-one (49%) questionnaires were returned. Non-participants did not differ from respondents with respect to gender or age (Binomial test, t-test p<0.1).

**End stage renal disease**
The end stage renal disease group included parents of all patients with end stage renal disease under treatment of the Emma Children’s hospital. A total of 38 families were eligible for this study. A reminder letter was sent to all parents after four weeks in order to increase response. Twenty-seven (71%) parents participated. The children of participants were either in dialysis (n=13) or transplanted (n= 14). Non-participants did not differ from participants with respect to age or gender distribution of the children with end stage renal disease (T-test; Binomial test, p<0.1).

**Metabolic diseases**
The metabolic group consisted of members of the Dutch patient organisation (Volwassenen en Kinderen met Stofwisselingsziekten, VKS, n=202) and parents of patients in the Emma Children’s hospital (n=32). A reminder was placed on the website of the VKS to increase participation. In total, 121 (52%) questionnaires were returned, 107 (53%) through the VKS and 14 (44%) from parents of patients from the Emma Children’s Hospital. The following three diagnosis groups were selected: lysosomal storage diseases (n=37, 31%), organic aci- durias (n=18, 15%), and mitochondrial respiratory chain defects (n=54, 45%). For 12 respondents (10%), the diagnosis group was not retrieved. Non-participants did not differ from participants with respect to age or gender distribution of the children with metabolic disease (T-test; Binomial test, p<0.1).

**Profound multiple disabilities**
The parents of children with profound multiple disabilities were invited through the specialized day-care centre that their children were attending. This day-care centre works closely with the Emma Children’s hospital. All 56 eligible families received a questionnaire. A reminder letter was sent to increase participation, which mentioned the possibility of getting help with filling out the questionnaire, as for many parents, neither Dutch nor English was their native language. In total, 21 (38%) parents participated. Information on non-participating families is not available.

**Sickle cell disease**
This group consists of parents of children with sickle cell disease who visited the outpatient clinic of the Emma Children’s hospital at least once during the previous year. All eligible parents (n=99) were invited to participate by mail. Parents who had not returned the questionnaire after two weeks were reminded by telephone or at their visit to the outpatient clinic (26). A total of 62 (63%) questionnaires were returned. Non-participants did not differ from participants with respect to age (T-test, p<0.1), but they did differ in gender distribution of
the children with sickle cell disease, with fewer girls in the non-participating group (Binomial test, p<0.1).

**Spina bifida**
This group included parents of all spina bifida patients under treatment at the Emma Children’s hospital. A total of 57 families were eligible for this study. Non-responders were contacted by phone and a reminder letter in order to increase response. Twenty-one (37%) parents participated. Non-participants did not differ from participants with respect to age or gender distribution of the children with spina bifida (T-test; Binomial test, p<0.1).

**Comparison group**
For the reference group, two elementary schools and one high school participated. The schools are located within 50 kilometers from the Emma Children’s hospital. Of two elementary schools, all parents (n= 560) received a letter explaining why the study was being conducted along with the questionnaire and a self addressed envelope. A total of 195 (35%) questionnaires were returned. Information on non-participants is not available. Further, a SES-matched control group (n=34) for caregivers of children with Sickle cell disease was added.¹ For the high school, we followed the same procedure as for the elementary schools. Half of the high school students (n=800) were given an envelope to take home for their parents. The final high school sample consisted of 277 (35%) questionnaires. Sixty-three parents had a chronically ill child and were excluded from analysis. In total, the comparison group consisted of 443 parents. Information on non-participants was not available.
