Additional file 1. Interview questions.

Patient characteristics

General characteristics about you [your child].

- Current age: … years.
- Age at which the first symptoms started: … years.
- Age at which the diagnosis 'deficiency of antibodies' was made: … years.
- Which diagnosis do you [your child] have?
- Which treatment do you / does your child receive?
    - Immunoglobulins?
    - Antibiotic prophylaxis?

If the interviewee is not the patient himself;

- What is your relationship to the patient?
    - Father / Mother

Introduction to the patient

I would like to hear about the time when you [your child] already had complaints, but the diagnosis 'deficiency of antibodies' had not yet been made.

- How long did that period last?
    - When did the complaints start?
    - When was the diagnosis definitely made (patient age)?
- Did the symptoms start suddenly or did they develop gradually?
- What were the complaints during this period?

Together we can try to sketch a short life course. Later, we will discuss the exact complaints and what they meant for you [your child].

- Infant (birth – 18 months)
- Toddler (18 months – 3 years)
- Child (3 years – 5 years)
- Elementary school (6 years – 12 years)
- High school; adolescence (12 years – 18 years)
- Twenties, thirties, et cetera

Medical history

General and central nervous system

- Can you tell me more about your [your child's] development?
    - Was the children's healthcare center satisfied about your [your child's] development?
    - Were you [your child] able to keep up with peers?
- Was there any weight change (decrease or increase)?
- Did you [your child] often have a fever?
    - If so, how often?
    - Was there a pattern in this?
- Do you [your child] have problems with hearing and/or seeing? Or any other problems with the senses (taste, smell, touch)?
- Did you [your child] have a headache, dizziness?
- Are there any memory problems?

Cardiorespiratory

- Did you [your child] have respiratory complaints?
- How is your [your child's] exercise tolerance?
- Did you [your child] feel fatigued?
    - If so, did this have an influence on daily activities?

Digestive system

- Did you [your child] have a stomach ache?

- Were there any nutritional problems at the time?
- What was your [your child's] stool pattern?

Urogenital
- Did you [your child] have complaints when urinating?

Allergies
- Do you [your child] have allergies?
  - If so, what are you [your child] allergic to?
  - Which symptoms do you [your child] experience after contact with these allergens?
  - Is this allergy confirmed with allergy diagnostics, such as blood- or skin prick test?

Medication
- Did you [your child] use any medicines in the period before the diagnosis 'deficiency of antibodies' was made?
  - If so, for what did you [your child] use these medicines?
  - Who prescribed these medicines?
  - How long did you [your child] take these medicines?
  - Did these medicines have (the desired) effect?
- Did you [your child] use any over-the-counter medications (for example, acetaminophen, aspirin, ibuprofen, oral contraceptive pills)?

Intoxication
- Do you [your child] consume alcohol?
  - How much?
- Do you [your child] smoke?
  - How many cigarettes a day? Since when?
- Do you [your child] use drugs?

Family history
- Are there first- and/or second degree family members with similar complaints?
- Have any first- and/or second degree family members been diagnosed with an immune disorder?
- Have any family members died (because of infections)? If children died at young age, was the cause of death known?
- Is there consanguinity?

Medical history
- Have you [your child] been diagnosed with other illnesses?
- Are you [your child] being treated by a specialist in hospital?
- Have there been repeated hospitalizations?

<u>Non-medical history</u>

Can you tell me more about the family in which you [your child] grew up?
- Parents?
- Brothers and/or sisters?
- Special circumstances?
- Living situation?

Can you tell me more about your [your child's] school-time?
- Which school did you [your child] complete (elementary school, high school)?
- Did you [your child] receive any education?
  - If so, which education?
  - How did this go?
  - Did you [your child] experience any problems?

Can you tell me more about your further adult life?

- Which career choices did you make?
- Did the complaints have consequences for the choices you made?
    - How, what would you have done differently if you had been free of these complaints?
    - Can you tell me more about that?

Can you tell me more about your [your child's] leisure activities?

- Do you [your child] practice a sport?
    - If so, which sport?
    - Performances?
- What are your [your child's] hobbies?

Can you tell me more about your [your child's] social life?

- Do you [your child] have friends?
- Do you [your child] ever go out?
- Did your [your child's] complaints entail restrictions?
- Do you [your child] have enough energy to undertake activities?