**Supplementary Table-1 (Card A). Initial patient information**

|  |  |
| --- | --- |
| Full name |  |
| Year of fulfillment |  |
| Date of birth |  |
| Diagnosis of immunodeficiency (descriptively + ICD-10) |  |
| Date of the diagnosis of deficiency + age at which the deficiency was diagnosed | Date: Age: |
| Year of the occurrence of the first symptoms + age when deficiency symptoms first appeared | Year: Age: |
| Comorbidities |  |
| Allergies (including information about intolerance to any immunoglobulin preparation) |  |
| Immunoglobulins that are administered to the patient (trade name, dose per kg of body weight, dose per month)Note: If the patient does not receive immunoglobulins, write: not applicable |  |
| Other drugs |  |
| Name and stamp of the center where the patient is treated |  |
| Name of the doctor who is treating the patient |  |
| Phone number of the center where the patient receives care ● Secretary’s office ● Nurses’ station● Doctor's office |  |
| Stimulants |  |
| Height (cm) |  |
| Bodyweight (kg) |  |
| BMI and nutritional status score: malnutrition(<18,5)/normal nutrition(18,5-24,9)/overweight(25,0-29,9)/obesity(≥30) |  |
| Vaccinations (in the case of indications or contraindications to vaccinations, this should also be included in this point, as well as information on the vaccinations received thus far) |  |
| Other important information |  |

**Supplementary Table-2 (Card B). Card of initial examinations and consultations—qualifying (performed during the diagnostic process and/or in the first year after the diagnosis)**

|  |
| --- |
| **Full name:** |
| **Current year:** |
| **Examination** | **Examination result (N/A)** | **Comments** |
| **Initial physical examination** |
| Bodyweight  |  |  |
| BMI | Result: \_\_\_ malnutrition(<18,5)/normal nutrition(18,5-24,9)/overweight (25,0-29,9)/obesity(≥30) | Underline as appropriate |
| BP+HR |  |  |
| Oral cavity |  |  |
| Nasal cavity |  |  |
| Ears |  |  |
| Lungs |  |  |
| Abdomen | LiverSpleenOthers |  |
| Lymph nodes |  |  |
| Skin |  |  |
| Others (please specify) |  |  |
| **Initial laboratory tests** |
| Complete blood count with manual differential |  |  |
| Creatinine1 |  |  |
| GFR1 |  |  |
| Glucose1 |  |  |
| AST1 |  |  |
| ALT1 |  |  |
| Alkaline phosphatase1 |  |  |
| GGT1 |  |  |
| LDH1 |  |  |
| β2-Microglobulin1 |  |  |
| ESR1 |  |  |
| CRP1 |  |  |
| Proteinography1 |  |  |
| Calcium1 |  |  |
| VitaminD31 |  |  |
| Vitamin B121 |  |  |
| Folic acid1 |  |  |
| Transferrin/ferritin1 |  |  |
| Uric acid1 |  |  |
| TSH andFT41 |  |  |
| Lipid profile1 |  |  |
| General urine test1 |  |  |
| Fecal occult blood test1 |  |  |
| HBS1 |  |  |
| Tumor markers1or3 |  |  |
| INR1 |  |  |
| APTT1 |  |  |
| IgA1 |  |  |
| IgG1 |  |  |
| IgM1 |  |  |
| IgG subclass1 |  |  |
| IgE1 |  |  |
| EBV PCR1or3 |  |  |
| CMV PCR1or3 |  |  |
| HCV PCR1or3 |  |  |
| HIV PCR1or3 |  |  |
| Others (e.g.serum amyloid A – SAA) |  |  |
| **Initial radiological examination** |
| Chest radiography/lung ultrasound1 |  |  |
| Chest CT/MRI2 |  |  |
| Abdominal ultrasound1 |  |  |
| Abdominal CT/MRI2 |  |  |
| Sinuses CT/MRI2 |  |  |
| Ultrasound of the lymph nodes1  |  |  |
| Thyroid ultrasound2 |  |  |
| Breast ultrasound/MRI\*,2 |  |  |
| Gynecologic ultrasound\*,2 |  |  |
| Testicular ultrasound\*\* |  |  |
| Echocardiography2 |  |  |
| Others: |  |  |
| **Initial endoscopic examination** |
| Gastroscopy2 |  |  |
| Colonoscopy2 |  |  |
| Bronchoscopy3 |  |  |
| Others |  |  |
| **Other examinations** |
| Spirometry1 |  |  |
| DLCO2 |  |  |
| Lymphocyte phenotyping1 |  |  |
| Fecal occult blood test2 |  |  |
| Microbiologic examination3 (e.g. parasite screening) |  |  |
| Cytology\* |  |  |
| Others: e.g.body plethysmography |  |  |
| **Consultations** |
| Dental2 |  |  |
| Ophtalmology2 |  |  |
| Otolaryngology2 |  |  |
| Gynecologic\*,2 |  |  |
| Urologic\*\*\*,2 |  |  |
| Psychological1 |  |  |
| Psychiatric1 |  |  |
| Dermatology1 |  | Indicated evaluation of moles |
| Others: |  |  |

1. Should be performed at the time of diagnosis
2. Should be performed within the first year after diagnosis
3. Decision about the examination/consultation belongs to the treating physician, in the absence of indications, please write: currently no clinical indications

\*applies to women

\*\*applied to men

\*\*\*applies to all men and women with urinary symptoms

Proposed abbreviations (physicians can fill in the table with these keywords, they were suggested for ease and standardization):

(N – the normal result, A - the abnormal result, NA - not applicable, CNCI - currently no clinical indications, DNC - did not consent, ITP - impossible to perform, e.g. due to contraindications or the patient's inability to perform, NPB - not performed before)

**Supplementary Table-3 (Card C) Card of control examinations and consultations**

|  |
| --- |
| **Full name:** |
| **Current year:** |
| **Examination** | **Date and result I****(N/A)** | **Date and result II****(N/A)** | **Recommended frequency** | **Comments** |
| **Physical examination (check-up)** |
| Bodyweight |  |  | Group 1 (Table A) -at least once a year Group 2At least twice a year |  |
| BMI |  |  | as above | Specify:malnutrition(<18,5)/ normal nutrition(18,5-24,9)/ overweight(25,0-29,9)/ obesity(≥30) |
| BP+HR |  |  | as above |  |
| Oral cavity |  |  | as above |  |
| Nasal cavity |  |  | as above |  |
| Ears |  |  | as above |  |
| Lungs |  |  | as above |  |
| Abdomen | LiverSpleenOthers |  | as above |  |
| Lymph nodes |  |  | as above |  |
| Skin |  |  | as above |  |
| Others (please specify) |  |  |  |  |
| **Follow-up laboratory tests** |
| Complete blood count with differential |  |  |  Group 1 (Table A) -at least every 1-2 yearsGroup 2-at least twice a year |  |
| Creatinine |  |  | as above |  |
| GFR |  |  | as above |  |
| AST |  |  | as above |  |
| ALT |  |  | as above |  |
| Alkaline phosphatase |  |  | as above |  |
| LDH |  |  | as above |  |
| Glucose |  |  | as above |  |
| ESR |  |  | as above |  |
| CRP |  |  | as above |  |
| General urine test |  |  | as above |  |
| Uric acid |  |  | Group 1 (Table A) -at least every 1-2 yearsGroup 2-at least once a year |  |
| Lipid profile |  |  | as above |  |
| Sodium  |  |  | as above |  |
| Potassium |  |  | as above |  |
| Proteinography |  |  | as above |  |
| β2-microglobulin |  |  | as above |  |
| Fecal occult blood test |  |  | as above |  |
| TSH |  |  | At least every 1-3 years |  |
| Calcium |  |  | as above |  |
| Vitamin D3 |  |  | as above | It is best to determine its concentration after the summer season |
| APTT |  |  | as above |  |
| INR |  |  | as above |  |
| Tumor markers1 |  |  | as above |  |
| Folic acid |  |  | as above | Additionally, in the case of anemia, malabsorption and polyneuropathy |
| Vitamin B12 |  |  | as above |
| Transferrin/ferritin |  |  | as above |
| HBS |  |  | Indicated in clinically justified situations |  |
| EBV PCR1 |  |  |  |
| CMV PCR1 |  |  |  |
| HCV PCR1 |  |  |  |
| HIV PCR1 |  |  |  |
| IgG |  |  | Group1- at least every 1-3 yearsGroup 2-IVIG- it is advisable to test before the next transfusion - SCIG - once every 3-6 months | Determining the main classes of immunoglobulins, despite disturbing their production, can help in the early detection of the presence of a pathological protein, e.g. a monoclonal protein |
| IgG subclass |  |  | Group 1-at least every 1-3 yearsGroup 2-indicated in clinically justified situations |
| IgA  |  |  | At least every 1-3 years |
| IgM |  |  | At least every 1-3 years |
| Others ( e.g.serum amyloid A – SAA) |  |  |  |  |
| **Follow-up radiological examination** |
| Examination (circle the appropriate examination) | Date and result of the examination (N/A) | Date of the next examination | Comments |
| Chest radiography/lung ultrasound2 |  |  | At least every 2 years (Group 1)1-2 times a year (Group 2) |
| Chest CT/MRI2 |  |  | CT (preferably HRCT) is recommended every 2-4 years (at least once every 5 years) in patients with documented and potentially progressive abnormalities in the lungs. At least 1 time in 5 years in patients with normal initial result (Group 2). In the case of a large number of CT examinations, MR is indicated |
| Abdominal ultrasound2 |  |  | At least every 2 years (Group 1)At least once a year (Group 2) |
| Abdominal CT/MRI2 |  |  | At least 1 time in 5 years in patients with normal initial result (Group 2). In the case of a large number of CT examinations, MR is indicated |
| Sinuses CT/MRI2 |  |  | 1 time in 5 years or less if the initial result is correct ( Group2) |
| Ultrasound of the lymph nodes2  |  |  | At least every 2-4 years |
| Thyroid ultrasound2 |  |  | Optimally once a year, at least once every 2 years |
| Breast ultrasound/MRI\*,2 |  |  | Optimally once a year |
| Gynecologic ultrasound\*,2 |  |  | Optimally once a year, at least once every 2 years |
| Testicular ultrasound\*\*,2 |  |  | Screening every 3 years |
| Echocardiography2 |  |  | At least every 5 years, and every 2-4 years in the case of mild cardiovascular diseases |
| Others: |  |  |  |
| **Follow-up endoscopic examination** |
| Examination | Date and result of examination (N/A) | Date of the next examination | Comments |
| Gastroscopy2 |  |  | At least every 3 years |
| Colonoscopy2 |  |  | At least every 3 years |
| Bronchoscopy4 |  |  |  |
| Others: |  |  |  |
| **Other follow-up examination** |
| Examination | Date and result of examination (N/A) | Recommended frequency | Comments |
| Spirometry |  | At least once a year |  |
| DLCO |  | At least once a year |  |
| Lymphocyte phenotyping |  | At least every 1-3 years |  |
| Microbiologic tests(e.g.parasite screening) |  | As needed, depending on the clinical condition |  |
| Cytology\* |  |  |  |
| Others: e.g.body plethysmography, densitometry |  |  |  |
| **Consultations** |
| Type of consultation | Date and result of examination (N/A) | Recommended frequency | Comments |
| Dental |  | At least twice a year |  |
| Ophthalmology |  | At least every 1-3 years |  |
| Otolaryngology |  | At least every 1-3 years |  |
| Rehabilitation |  | At least once a year | To teach and control pulmonary rehabilitation |
| Gynecologic\* |  | At least once a year |  |
| Urologic\*\*\* |  | At least once a year |  |
| Dermatology |  | At least once a year | Evaluation of moles |
| Psychological1 |  |  |  |
| Psychiatric1 |  |  |  |
| Oncology1 |  |  |  |
| Others: |  |  |  |

1. Decision about the examination/consultation belongs to the treating physician, in the absence of indications, please write: currently no clinical indications
2. Routine frequency of examinations described in the text, additionally indicated in clinically justified situations

\*applies to women

\*\*applied to men

\*\*\*applies to all men and women with urinary symptoms

Proposed abbreviations (physicians can fill in the table with these keywords, they were suggested for ease and standardization):

(N – the normal result, A - the abnormal result, NA - not applicable, CNCI - currently no clinical indications, DNC - did not consent, ITP - impossible to perform, e.g. due to contraindications or the patient's inability to perform, NPB - not performed before)