|  |
| --- |
| Name or ID |

Department \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Physician \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Date \_\_\_/\_\_\_/\_\_\_\_\_\_ (dd/mm/yy)

Always draw a family tree

|  |
| --- |
| Consanguinity O no O yes |

**Initial pulmonary diagnosis**

**Initial non-pulmonary diagnosis**

Patient´s nationality \_\_\_\_\_\_\_\_\_\_ language \_\_\_\_\_\_\_\_\_\_\_\_

Parent´s ethnicity Mother O Caucasian O other (which): \_\_\_\_\_\_\_ \_\_\_\_\_\_\_\_\_ Father O Caucasian O other (which): \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Patient´s occupation Mother´s occupation Father´s occupation

Chronic diseases or deaths of relatives

caused by interstitial lung disease? O no O yes\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_(who/what)

caused by other diseases? O no O yes\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_(who/what)

Gestational age \_\_\_\_\_ WGA if unknown: \_\_\_\_\_ term/ preterm Birth-weight \_\_\_\_\_ g

Respiratory symptoms after births O no O yes

Need for oxygen after births O no O yes for \_\_\_\_\_ days

Need for ventilation after births O no O yes for \_\_\_\_\_ days

Start of lung disease \_\_\_/\_\_\_ (date mm/yy) or \_\_\_\_\_\_ (age in months)

Date of diagnosis \_\_\_/\_\_\_ (date mm/yy) or \_\_\_\_\_\_ (age in months)

Start of disease O gradually O suddenly O suddenly after infection O unknown

|  |
| --- |
| **Minor neural dysfunction**  Fine manipulative disability O no O yes  Dyscoordination O no O yes  Choreiform Dyskinesia O no O yes  Dysfunctional posture and muscle tone O no O yes  Dysfunctional Reflexes O no O yes  Excessive associated movements O no O yes  Sensory deficits O no O yes  Cranial nerve dysfunction O no O yes |

**History of exposure (EPR-3)**

diagnosis of Asthma (by physician) O no O yes

family members with diagnosis of Asthma O no O yes

atopic allergies O no O yes

recurrent difficulty in breathing O no O yes

history of recurrent wheezing O no O yes

history of cough O no O yes

worsening of symptoms (after exercise) O no O yes

pets in household O no O yes

mould in household O no O yes

birds/ feather exposure O no O yes

**Co-morbidities**

1 Failure to thrive, 2 Autoimmune, 3 Immuno-deficiency, 4 heart, 5 Gut, 6 Kidney, 7 Liver, 8 Lymph.-System, 9 Musculoskeletal, 10 Nervous-System, 11 Skin/Dermatomorphic sign, 12 Thyroid, 13 Other

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| Name or ID |

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Department \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Physician \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Date \_\_\_/\_\_\_/\_\_\_\_\_\_ (dd/mm/yy)

Disease \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

|  |
| --- |
| Weight \_\_\_\_\_ kg/ change \_\_\_\_ kg/ P\_\_\_\_\_  Length \_\_\_\_\_ cm/ change \_\_\_\_ kg/ P\_\_\_\_\_  Respiratory rate \_\_\_\_\_/min  Heart rate \_\_\_\_\_/min  RR \_\_\_\_\_/\_\_\_\_\_ mmHg O2 saturation \_\_\_\_\_/%  Need of O2 O no O yes \_\_\_ l/min  5 min without O2 Saturation \_\_\_\_\_ % |

**History since last visit**

Pulmonary exacerbation O no O yes (if yes use extra sheet EXACERBATION)

|  |
| --- |
| Dyspnoea O no O yes Start: \_\_\_/\_\_\_\_  Tachypnea O no O yes Start: \_\_\_/\_\_\_\_  Cough O no O yes Start: \_\_\_/\_\_\_\_  Retractions O no O yes Start: \_\_\_/\_\_\_\_  Hemoptysis O no O yes Start: \_\_\_/\_\_\_\_  Gastroesophageal reflux O no O yes Start: \_\_\_/\_\_\_\_  Recurrent aspirations O no O yes Start: \_\_\_/\_\_\_\_ |

|  |
| --- |
| **Medication** (if more than 3 use extra sheet MEDICATION) |

|  |  |  |
| --- | --- | --- |
| Physician’s opinion:  “The course of disease is…” | o healthy  o sick-better  o sick-same  o sick-worse  o dead | |
| Patient´s/Parent’s opinion:  “How do you feel? Please give a number from 1 (“very bad”) to 10 (“fine”).” | | \_\_\_\_\_ (1-10) |

|  |
| --- |
| Fan 5 point severity scale  O Asymptomatic  O Symptomatic, normal room air oxygen saturation under all conditions  O Symptomatic, normal resting room air saturation, but abnormal saturation (< 90%) with sleep or exercise  O Symptomatic, abnormal resting room air saturation  O Symptomatic with pulmonary hypertension |

**Examination findings Vaccinations** O no O yes \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

**New comorbidities** O no O yes \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

**Diagnostics** (use extra sheet DIAGNOSTICS)

**Plan/ changes in medication/ next visit**

**Medication**

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| name / dosage / application: | Date: | Date: | Date: | Date: |
|  | Status (on/off- when) | Status (on/off- when) | Status (on/off- when) | Status (on/off- when) |
|  | Start: | Start: | Start: | Start: |
| Stop: | Stop: | Stop: | Stop: |
|  | Start: | Start: | Start: | Start: |
| Stop: | Stop: | Stop: | Stop: |
|  | Start: | Start: | Start: | Start: |
| Stop: | Stop: | Stop: | Stop: |
|  | Start: | Start: | Start: | Start: |
| Stop: | Stop: | Stop: | Stop: |
|  | Start: | Start: | Start: | Start: |
| Stop: | Stop: | Stop: | Stop: |
|  | Start: | Start: | Start: | Start: |
| Stop: | Stop: | Stop: | Stop: |
|  | Start: | Start: | Start: | Start: |
| Stop: | Stop: | Stop: | Stop: |
| Need of oxygen | Start: | Start: | Start: | Start: |
| Stop: | Stop: | Stop: | Stop: |
| Invasive ventilation (inclusive mode and settings) |  |  |  |  |
|  |  |  |  |  |
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| --- |
| Name or ID |

Department \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Physician \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Date \_\_\_/\_\_\_/\_\_\_\_\_\_

**Spirometry** O no FEV1 (L) \_\_\_\_\_ FEV1 (% pred) \_\_\_\_\_

**FVC (L) \_\_\_\_\_ FVC (% pred) \_\_\_\_\_** MEF25-75 (l/s) \_\_\_\_\_ FEF25-75 (% pred) \_\_\_\_\_

**Gas transfer** O no DLCO (ml/min/mmHg) \_\_\_\_\_ DLCO (%) \_\_\_\_\_

**Blood gas** O no Arterial/capillary/ venous blood gases PaO2 (mmHg): \_\_\_\_\_ PaCO2 (mmHg) \_\_\_\_\_

**6 min walk test:** O no **Distance (m) \_\_\_\_\_** at rest immediately after exercise

Oxygen-Saturation \_\_\_\_\_ % \_\_\_\_\_ %

Heart rate \_\_\_\_\_/min \_\_\_\_\_ /min

Borg-Scale \_\_\_\_\_ (1-10) \_\_\_\_\_ (1-10)

**Echocardiography** O no Pulmonary Hypertension O no O yes

Estimated mean pulmonary artery pressure (mmHg): \_\_\_\_\_\_\_(Right heart catheter)….?

**Chest X-ray:** O no  **=> upload or send on CD**

|  |
| --- |
| PatientO no O yes  Mother O no O yes  Father O no O yes |
|  |

**HRCT-scan:** O no **=> upload or send on CD**

**Blood sampled (EDTA tubes and PAX/Tempus) for shipping to Biobank**

**Lab values:**

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
|  | Not done | Result | Unit | Normal | Ab-normal |
| LDH |  |  | U/l |  |  |
| ANA |  |  | Titer |  |  |
| c-ANCA[Proteinase 3 ANCA, Wegener] |  |  | U/ml |  |  |
| p-ANCA[Myeloperoxidase ANCA, Churg-Strauss] |  |  | U/ml |  |  |
| Hb (if abnormal give lowest value) |  |  | g/dl |  |  |
| Eosinophils |  |  | % |  |  |
| absolute |  |  | /µl |  |  |
| White cell count (absolute) |  |  | /µl |  |  |
| Immunoglobulines - IgG |  |  | mg/dl |  |  |
| Immunoglobulines – IgA |  |  | mg/dl |  |  |
| Immunoglobulines – IgM |  |  | mg/dl |  |  |
| Immunoglobulines – IgE |  |  | U/L |  |  |
| GMC SF**-**autoantibodies [Autoimmune PAP] |  |  | ng/ml |  |  |
| Bird-IgG-antibodies [bird precipitins] |  |  |  |  |  |
| Fungus IgG antibodies [fungi precipitins] |  |  |  |  |  |
| Aspergillus lgE |  |  |  |  |  |
|  |  |  |  |  |  |

**EXACERBATION**

**Barcode**

Date: \_\_\_\_\_\_\_\_\_\_\_ Physician: \_\_\_\_\_\_\_\_\_\_\_\_\_

**Please 1 sheet per exacerbation**

Patient at the end again in previous baseline - state?

O No, O Yes

Start date \_\_- \_\_- \_\_\_\_ End date \_\_- \_\_- \_\_\_\_

DD-MM-YYYY DD-MM-YYYY

**Please check the “7-criteria”:**

1. Increase in respiratory rate O No, O yes O nd

2. Increase or development of dyspnea O No, O yes

3. Newly developing or increased abnormalities on chest imaging O No, O yes O nd

4. Onset/increase of oxygen demand to attain the individual baseline saturation O No, O yes

5. Need for an additional level of ventilatory support (in addition to oxygen) O No, O yes

6. Decrease in lung function in children able to perform the tests O No, O yes O nd

7. Reduced exercise tolerance (history or in tests) O No, O yes

**Additional info**

1. Was the patient hospitalized? O No, O yes

2. New feeding problems O No, O yes

3. New failure to thrive/weight lost O No, O yes

4. Was there a change in treatment O No, O yes => What was done?\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

**Cause/trigger** (multiple selection possible)

1. Infection O No, O yes

2. Exposure to environmental irritant O No, O yes

3. Aspiration O No, O yes

4. Extra-pulmonary processes O No, O yes

5. Changes of treatment prior worsening O No, O yes

6. Poor treatment adherence O No, O yes

7. Side effect of current medication O No, O yes

8. Psychosocial factors O No, O yes

**Remarks:**